Parenting a Child Recipient of Proton Beam Therapy: Experience, Expertise and Recovery

by

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Abstract

Proton Beam Therapy (PBT) is a new type of therapy used to treat rare and complex tumours. PBT is claimed to improve patients’ quality-of-life by reducing treatment-related side effects and the risk of long-term complications; although long-term evidence for this is limited. Since 2008, NHS patients have had access to proton treatment through a government funded scheme, although access is restricted to an eligible list of users. Since the start of this scheme, the majority of treated patients have been paediatric patients. This research examines the experiences of parents of paediatric patients, treated with proton therapy. This is the first piece of research to examine users’ experiences involving proton treatment. Proton beam therapy is a new type of treatment and it is not known how users experience, perceive and make decisions involving this treatment.

This is a qualitative inquiry based on joint and single interviews, carried out with 27 parents; eight fathers and 19 mothers. Participants were recruited via an online support group, as well as charities. A total of 21 families participated in this study; two families fell into the category of ‘self-funded’, meaning they opted for proton therapy against the advice of their child’s primary team of doctors and privately raised funds for treatment. The remaining families were sponsored by the NHS. Additionally, discourse analysis of patient information documents related to proton treatment was conducted. Juxtaposing the outcome of the discourse analysis with the accounts presented by parents in their interviews sheds insight into the different perspectives and experiences, if any, and enables us to look at whether and where contrasting views are reflected and reproduced, and the implications these may have.

The way parents view and understand PBT and approach decision-making about this new therapy, and other treatments, are explored in this study. Additionally, this research situates parental knowledge and work, deployed in the management of their child’s illness and treatment, as expertise. Through attaining this expertise parents reclaim some order of control, protect their parental role and responsibility and manage some of their uncertainties. Exploration of these parents’ post-treatment accounts highlights a range of on-going health issues and uncertainties, some specific to PBT, which impede aspects of their child’s recovery. The literature on recovery is primarily focused on an individualistic adult patient perspective, however this research conceptualises recovery from childhood illnesses as a joint venture shared between parent(s) and child. Findings presented in this thesis contribute to the sociology of health and illness, and family studies, by providing insight into the experiences of parents of paediatric patients treated with proton therapy. It also contributes to sociological literature on expertise and recovery.
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To my parents...
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Chapter 1: Introduction

In September 2014, the case of Ashya King was the focus of a media frenzy, public discussion and political debate; with leading political figures such as David Cameron and Nick Clegg weighing in on the case. Following the completion of surgery on Ashya’s cancerous brain tumour, conflict arose between his parents and medical team. The Kings did not agree with the follow-up treatment plan proposed by the medical team, i.e. X-ray radiation therapy, due to the fact that they regarded this approach as “trial-and-error” and did not want their son, Ashya, to be “pelted with radiation” (Brett King, BBC 2014). Having searched for a different and less debilitating treatment plan, the Kings sought an alternative treatment in the form of Proton Beam Therapy (PBT); a form of radiation therapy considered able to deliver effective targeted radiation at a reduced risk of toxicity. Based on their own view of what would be better treatment for their child, the Kings took their son out of the care of the UK based hospital and travelled abroad in pursuit of this alternative treatment. What followed was an international hunt for Ashya and his parents, since doctors advocating the original treatment plan feared for the child’s safety and wellbeing. Following an initial public outcry towards the parents, who were thought to have behaved irresponsibly by placing Ashya’s life in danger (see BBC 2014a and The Guardian 2014 for examples), the revelation that the Kings were in search of, what they perceived to be, a ‘better’ mode of treatment for their son resulted in an expression of concern aimed towards the medical team and the NHS.

This research was formulated and proposed prior to the case of Ashya King, with a focus on paediatric users of proton therapy¹. The incident is used as a point of reference however, since

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¹ Proton therapy, proton treatment and PBT are used interchangeably throughout this thesis.
it highlights the potential role of PBT in the management of childhood cancers and neatly encapsulates and contextualises some of the core issues which are at the heart of this study. It teases out the complex nature of the doctor and parent relationship and the potential for conflict and challenges to medical authority. Furthermore, it highlights uncertainties surrounding medical knowledge and technologies which subsequently impact notions of disease and decision-making. This thesis focuses on the views and experiences of parents whose child was diagnosed with a tumour and treated with PBT.

It is worthy of mention, at the forefront of this thesis, that parents’ accounts involving their child’s thoughts and feelings have been excluded from analysis. This is because, as researcher, I am aligned with the view which recognises children as active agents who possess the ability to interact and engage with people, institutes and ideologies and therefore have their own experiences and understandings (Prout and James 2014). Research has demonstrated that the use of suitable and appropriate methodology can facilitate and encourage children to participate in research studies (Whiting 2015, Gibson et al. 2010, Bendelow et al. 1996). It is suggested that any effort to produce a social science account of the experiences of childhood illnesses, which does not adequately and equally incorporate the views of the young patients as well as their parents’ is thought to be incomplete; to study one without the other is to risk producing a partial account of the experience (Dixon-Woods et al. 2005). Despite efforts to include young patients within this study, restraints imposed by ethics committees meant that this research did not have access to the children and young people. This limitation is further discussed in the methodology chapter and Chapter 9. Therefore, based on the view that children and young people have their own agency and, given the correct tools, can share and articulate their own experiences, the decision was made to not rely on their parents’ views as proxies and to solely focus on the voices which the research had access to.
To better understand the focus of this study, an introduction to the clinical background of proton therapy, its position within the NHS context and use for treatment of paediatric diseases is provided. Attention then shifts to the aims of this project, and the adopted methodological approach is explained. Lastly, an outline of the structure of the thesis is provided.

1.1 Proton Beam Therapy

Proton Beam Therapy is a ‘novel’ form of particle radiation treatment, which makes use of protons rather than conventional photons. A proton is a positively charged particle, which forms the basic unit of an atom. If given the right amount of energy a proton can be used in a similar way to a photon i.e. X-ray, in order to destroy cancer cells (Levin et al. 2005 and Clair et al. 2004). One of the desirable characteristics of protons is their ability to deliver a dose of radiation in a much more confined way to the targeted site. This unique energy absorption profile enables the delivery of a beam across the intended target volume followed by a very rapid energy loss in the last few millimetres of penetration. This results in a sharply localised dose peak, known as the Bragg peak; Figure 1 is an illustration of the Bragg peak. The penetration depth of the Bragg peak is directly related to the initial energy of the charged particle; the rationale for the use of proton therapy rests on this unique property (McDonald and Fitzek 2010).
Chapter 1: Introduction

Figure 1: Proton Bragg Peak; a proton brag peak demonstrates the energy deposition that occurs at the termination of the proton path (Source: McDonald and Fitzek 2010, p 258)

This regulated dose deposition allows for highly charged protons to penetrate a precise distance within the body and consequently deliver a specific dose of radiation to the desired location. A specific dose of radiation is delivered to the tumour site, whilst emitting smaller doses to the surrounding tissue or no exit radiation at all (Fossati et al. 2009, Levin et al. 2005). As a result, protons cause less damage to healthy tissues lying in front of the tumour, and no damage to the healthy tissue positioned behind the tumour; these physical properties of protons provide a distinct advantage over photons (Allen et al. 2012). Photon radiation (X-ray radiation) continues to deposit energy leading to radiation doses in healthy tissues beyond the tumour site, as they exit the patient’s body; the contrasting behaviours of protons and photons are demonstrated in Figure 2.
Figure 2: Proton Beam Behavior: proton beams can be energised so that they are targeted at the desired penetration with the highest (peak) amount of energy, with low radiation energies below this penetration depth and almost zero radiation beyond it. In contrast, conventional X-rays, i.e. photons, have highest amount of energy at low penetration depths and the energy attenuates after the peak at the low penetration depths. (Source: ProNova Solutions 2014)

The following image, Figure 3, illustrates a typical PBT delivery setup. A machine known as a ‘Synchrotron’ generates and accelerates the proton beam, which is steered by magnets to the individual treatment rooms. Patients may spend up to one hour per day in the treatment room; these patients will be fitted into a special immobilisation device in order to ensure they remain still throughout treatment. Often is the case that younger patients undergo anaesthesia in order to ensure they remain immobile. For these young patients, time spent in the treatment and recovery room may last up to four hours. The treatment is painless; however, the machine can be noisy. Due to the radiation nature of the treatment, parent(s) are not allowed to accompany their child during treatment. The patient must remain alone in the treatment room, where they are monitored through CCTV (NHS 2013).
1.1.1 Benefits of Proton Beam Therapy

The aim of cancer therapies is to destroy or remove cancerous tissues, whilst limiting the damage to healthy organs (Paganetti 2017). Proton therapy is regarded as an effective mode of cancer therapy since the high precision targeting nature of the treatment increases the effectiveness of therapy and disease control, whilst the comparatively lower dose bath is thought to reduce risks of toxicity and damage to healthy tissues (DoH 2012). These features not only improve the quality-of-life for patients receiving therapy, by reducing treatment related side effects such as low blood counts and nausea, but also reduce the risk of long-term toxicity and complications often resulting from other conventional radiotherapy (Paganetti 2017). Owing to these properties, proton therapy is considered to be particularly revolutionary in treating paediatric cancers and cases where the tumour is in close proximity to critical
structures, since it is less likely to harm healthy and developing tissues (Allen et al. 2012, Levin et al. 2005).

It is important to note that whilst there is evidence to support the benefits of proton therapy over photon radiation approaches, further clinical trials and long-term evidence are encouraged (Crellin 2018, Deville 2016 and Allen et al. 2012). According to Crellin (2018), although survival and local control of some diseases treated with PBT, are equivalent to photon treatment, it is still too early to assess late toxicity of treatment. Compared to photon therapy, there are major uncertainties concerning proton therapy and the NHS has tried to ensure these uncertainties are managed and addressed safely by treating patients within an academic environment, and linked to high-quality follow-up and outcome analysis (Crellin 2018). Addressing gaps in the evidence through further research and clinical trials is key to addressing the uncertainties of PBT, and should be a priority moving forward with the NHS proton scheme.

According to Crellin, that PBT is more effective and/or without toxicity, compared with conventional radiotherapy is a “mythology” (p279). The public, and cancer patients especially, can be vulnerable to the exaggerated claims made by the commercial sector, and it is therefore ethically important that professionals do not oversell proton therapy, and address these uncertainties.
1.2 Childhood Cancers and Proton Beam Therapy

Cancer is the main category of disease treated with proton therapy, and the national PBT service is a key part of the government’s strategy for improving the outcomes of cancer (DoH 2011, 2012a). Cancer is the leading cause of death by disease in young children in the United Kingdom (Cancer Research UK 2017). Over the past decades however, due to major advances in diagnosis and treatment, children’s cancer survival has more than doubled. Reports suggest that approximately three-quarters of children diagnosed with cancer will survive their disease for five years or more; and most of these children will be cured (Cancer Research UK 2017). This significant improvement in the rates of survivorship has resulted in childhood cancer being recognised as a chronic illness (Brown 2006). Unfortunately however, the successful increase of survival rates, resulting from advances made in treatment, are often juxtaposed with potentially devastating side effects and a detrimental impact on the patient’s quality-of-life (NHS 2015, Landolt et al. 2006 and Clair et al. 2004).

This section provides a generic outline of paediatric cancer status and statistics in the UK, and the benefits of the use of PBT as a treatment option.

1.2.1 Incident Rates of Childhood Cancer

In the UK, approximately 1,800 children (0-14 years) are diagnosed with cancer each year; this figure is inclusive of benign (non-cancerous) tumours as well (Cancer Research 2017). The most common types of childhood cancer are leukaemias and cancers of the brain and spinal cord (ibid).

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2 Diseases treated with proton therapy are not only limited to cancer; non-cancerous tumours are also treated with Proton Beam Therapy (NHS 2011).
Brain and Central Nervous System (CNS) tumours are the second most common form of childhood cancer in Britain. Figures published in 2014 suggest that more than 400 new cases of CNS types of cancers are diagnosed each year in the UK; making up almost a quarter (~26%) of childhood cancer cases (Cancer Research UK 2014). Leukaemia is the most common type of diagnosed cancer in children, accounting for 31% of all cases. The following diagram, Figure 4, illustrates the incidence of the main types of childhood cancer in the UK.

![Pie chart showing incidence of main types of childhood cancer in the UK.](image)

**Figure 4: Incidence of the Main Types of Childhood Cancer in the United Kingdom. (Source: Children with Cancer UK 2014)**

### 1.2.2 Treatment Options

Surgery, chemotherapy, radiotherapy and targeted cancer drugs are common forms of treatment used for childhood cancers and tumours. There are a number of side effects associated with these therapies, however these are normally short lived and can be alleviated
by use of medication. Yet, in some instances significant side effects such as growth deficiencies, fertility problems, mild cognitive impairment and second forms of cancer may arise (Fossati et al. 2009 and Clair et al. 2004). Side effects attached to radiotherapy are especially debilitating and wide ranging. Whilst irradiating healthy tissue is harmful to any cancer patient of any age, it may be most harmful to young children since their bodies are still developing and are more susceptible to the effects of radiation (NHS 2015). Radiation therapy in children is thought to impair growth, development of soft tissues, bone and nerves and has a profound effect on the developing brain of young children (Allen et al. 2012). Treating brain tumours with radiation therapy is known to increase the risk of developing additional brain tumours later in life. Due to these reasons, health professionals avoid giving radiation to young patients, and will only subscribe to this treatment based on very careful consideration (The Brain Tumour Charity 2018).

Owing to the characteristics of proton treatment, i.e. its ability to deliver radiation to a precise target with minimum damage to surrounding tissue, the role of radiation therapy in paediatric cancer treatments has expanded (NHS 2018, Merchant 2013). Figure 5 and Figure 6 offer a visual depiction of proton and X-ray radiation beam patterns in the treatment of brain tumours.
1.2.3 Proton Beam Therapy for Childhood Cancers

Discussing the benefits of PBT, Clair and colleagues (2004) suggest that the advantages raised by this treatment are particularly important and useful for the treatment of childhood malignancies, due to the rapid and progressive anatomic and neurocognitive development that occurs in this population. It is suggested that proton therapy has the ability to reduce the occurrences of significant long-term or short-term side effects such as growth problems, poor IQ development, hormone deficiencies, loss of hearing, fertility problems and the risk of developing a secondary form of cancer, which often result from conventional radiation...

1.3 Proton Beam Therapy on the NHS

In this section, the service and provision of proton therapy under the NHS is outlined. PBT is classified as a highly specialised service, where access is regulated by a governing panel. NHS patients access treatment via an overseas scheme, which sends select groups of patients to treatment centres based in the United States and Switzerland. Most recently however, Manchester Christie has become home to the first high energy proton therapy centre in the UK.

1.3.1 Highly Specialised Services

Proton therapy is classed as a highly specialised service under the NHS (NHS 2018). Highly specialised services are facilities aimed at rare and complex conditions, and for this reason are delivered nationally through a small number of centres of excellence. These commissioned services are delivered to a small pool of patients, usually no more than 500 patients per year (NHS 2018).

Clatterbridge Cancer Centre was the first NHS Foundation Trust to offer PBT facilities. However, this centre delivers low energy proton therapy for patients with eye tumours only. The British Government is heavily invested in proton technology, with a £250m project dedicated to building two proton centres across England; University College London Hospital (UCLH) and the Manchester Christie. The Manchester Christie recently became operational,
having treated their first young patient in January 2019, and the UCLH is expected to become operational in 2020. It is anticipated that each centre will treat between 650-750 patients per annum (Crellin 2018).

Whilst waiting for these high-energy proton centres to become operational in the UK, NHS patients who are deemed to benefit the most from proton therapy have had access to this treatment via a government funded programme, ‘NHS Proton Overseas Programme’, which sends patients to be treated in American or other European centres.

1.3.2 NHS Proton Overseas Programme

Since April 1st 2008 funding has been provided for proton therapy to treat certain types of cancer, and some non-cancerous tumours (NHS 2018). Until quite recently, patients have been referred overseas for treatment. A clinical panel is responsible for reviewing cases and deciding whether the case is suitable for proton treatment abroad. The following centres work in partnership with the NHS under this scheme;

- ProCure, Oklahoma City, Oklahoma, USA
- University of Florida Proton Therapy Institute, Jacksonville, Florida, USA
- The Paul Scherrer Institute, Villigen, Switzerland

To date most patients have been treated at University of Florida Proton Therapy Institute (Crellin 2018).

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3 In January 2019, it was announced that Mason Kettley was to commence treatment as one of the first UK proton-beam NHS patients, (Source: BBC News 2019).
Depending on their treatment plan patients, and their accompanying carers, are expected to be away from home for approximately eight-10 weeks. The NHS will cover the following expenses during this period:

- The cost of treatment and any other treatment related to the course of Proton Beam Therapy
- The costs of travel and transport; for paediatric patients, the NHS will fund travel costs for two parents/carers accompanying the patient. For adult patients, the NHS will fund the travel costs of one accompanying carer only.
- The cost of accommodation for the duration of treatment
- Economy return flights
- Car hire and public transport costs
- ESTA travel waivers
- Travel insurance (NHS 2013a)

1.3.3 Proton Clinical Reference Panel

Access to treatment is regulated by a clinical review panel. If a patient’s consultant feels that proton therapy might be a suitable treatment, they make a referral to the Proton Clinical Reference Panel (PCRP) and request approval based on the patient’s medical reports. The PCRP is a multidisciplinary team comprised of two teams, adult specialists and paediatric specialists. The panel is responsible for managing the referral pathway and has necessary knowledge of proton therapy required to consider and approve cases for treatment; measures of cost effectiveness as well scientific evidence, although scarce, inform and support the use of this technology (NHS 2011). Following this, the experts at the treating centre will make the
final decision to accept cases for treatment, after approval from the PCRP. Figure 7 depicts the referral pathway;

![Referral Pathway for Proton Beam Therapy](image)

Figure 7: Referral Pathway for Proton Beam Therapy. (Source: NHS 2011)

The list of users eligible for treatment is restricted to an approved list of diagnoses, see Table 1. This list is devised by a national expert panel and dependent on many criteria such as the patient’s age and ability to travel, see Table 2; diagnosis alone is often insufficient for approval. Further criteria for treatment approval are outlined in Appendix I.
Table 1: List of Approved Paediatric Diagnoses. (Source: NHS 2011)

<table>
<thead>
<tr>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base of Skull and Spinal Chordoma</td>
</tr>
<tr>
<td>Base of Skull and Chondrosarcoma</td>
</tr>
<tr>
<td>Spinal and Paraspinal ‘adult type’ Bone and Soft Tissue Sarcomas</td>
</tr>
<tr>
<td>Rhabdomyosarcoma</td>
</tr>
<tr>
<td>- Orbit</td>
</tr>
<tr>
<td>- Parameningeal and Head and Neck</td>
</tr>
<tr>
<td>- Pelvis</td>
</tr>
<tr>
<td>Ependymoma</td>
</tr>
<tr>
<td>Ewing’s Sarcoma</td>
</tr>
<tr>
<td>Retinoblastoma</td>
</tr>
<tr>
<td>Pelvic Sarcoma</td>
</tr>
<tr>
<td>Optic Pathway and other selected Low-Grade Glioma</td>
</tr>
<tr>
<td>Craniopharyngioma</td>
</tr>
<tr>
<td>Pineal Parenchymal Tumours (not Pineoblastoma)</td>
</tr>
<tr>
<td>Esthesioneuroblastoma</td>
</tr>
</tbody>
</table>

The decisions to include these items on the list of approved diagnoses is based on rates of survival and priori evidence of dosimetry benefits (Glaser et al. 2014). It is noteworthy that the NHS’ list of eligible patients for PBT is different to that of the proton centres working in partnership with it. For example, whilst the NHS does not approve funding for paediatric Medulloblastoma and ATRT tumours, the UF proton institute will treat this type of paediatric tumour with proton therapy. Furthermore, it is important to highlight that not all of the NHS approved diagnoses are cancerous; Craniopharyngioma for example is a benign form of tumour.
Table 2: Factors taken into account in assessing if PBT confers significant advantage over conventional radiotherapy. (Source: NHS 2011)

<table>
<thead>
<tr>
<th>Timing of radiotherapy in relation of other treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site of Tumour</td>
</tr>
<tr>
<td>Radiotherapy target volume</td>
</tr>
<tr>
<td>Target volume dose and dose gradient required</td>
</tr>
<tr>
<td>Tumour and target volume proximity to critical dose limiting structures</td>
</tr>
<tr>
<td>Patient age and performance status</td>
</tr>
<tr>
<td>Stage and pathology</td>
</tr>
<tr>
<td>Presence, size and position of metallic implants</td>
</tr>
<tr>
<td>Views of patients/parents</td>
</tr>
<tr>
<td>Patients’ ability to Travel</td>
</tr>
</tbody>
</table>

The overall number of patients treated overseas to date has been less than anticipated, however the cases of paediatric referrals have been escalating (Cancer Research UK 2013, DoH 2012). Data accessed via Parliament UK provides an annual breakdown of paediatric patients treated with PBT, see Table 3; this data runs from the year 2009.

Table 3: Number of Patient who had applications approved for proton treatment overseas since 2009. (Source: Parliament UK 2015)

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Approved</th>
<th>Number of Paediatric Patients</th>
<th>Proportion of Paediatric Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009-2010</td>
<td>20</td>
<td>8</td>
<td>40%</td>
</tr>
<tr>
<td>2010-2011</td>
<td>50</td>
<td>30</td>
<td>60%</td>
</tr>
<tr>
<td>2011-2012</td>
<td>79</td>
<td>66</td>
<td>84%</td>
</tr>
<tr>
<td>2012-2013</td>
<td>99</td>
<td>83</td>
<td>84%</td>
</tr>
<tr>
<td>2013-2014</td>
<td>124</td>
<td>103</td>
<td>83%</td>
</tr>
</tbody>
</table>
Since the start of the programme in 2008, 65% of referrals have been for paediatric cases (Crellin 2018). The definition of ‘paediatric’ is taken as up to, but not including, the 16th birthday of the patient at the date of receipt of a complete referral to the panel (NHS 2011).

1.4 Focus of this Study

Proton therapy is a new type of treatment, largely used to treat paediatric diseases. It is not known how users of the technology perceive the treatment, how they approach decision-making, and what their experiences involving treatment are. In comparison to conventional radiation treatment, proton therapy is depicted as an advance mode of therapy capable of reducing long-term side effects; although long-term evidence for this claim is limited. For NHS patients, access to PBT is restricted to a pre-approved list of patients and not everyone is eligible for treatment. However, given that the proton centres abroad treat a wider variety of tumours, some patients may access proton therapy by self-funding. This research will look at how parents of children treated with proton therapy perceive and understand treatment, what informs their views of treatment and how they approach decision-making involving this new type of treatment. The study will aim to access the voice of NHS and non-NHS funded families in order to draw comparison, and see whether they hold different views of treatment for example.

Parents play a key role within their child’s experiences of illness. In the context of their child’s illness, parents become protectors, decision makers and advocators (Shortman et al. 2013, Woodman 2013, Bluebond-Langner et al. 2007, Hallström et al. 2002). The case of Ashya King drew attention to the contested role of parents, and suggests that in the context of PBT there is potential for conflict between parents and clinicians regarding treatment decision-
making involving paediatric patients and proton treatment. This research will examine the role and experiences of parents whose child has undergone proton treatment.

### 1.5 Methodology

This is a qualitative inquiry based on interviews carried out with parents of paediatric patients treated with proton therapy. Findings presented within this thesis are based on qualitative interviews with 27 parents, eight fathers and 19 mothers. Six joint interviews, consisting of mother and father, and 15 single interviews were conducted. Of the 21 families involved, 19 were funded by the NHS and the remaining two were self-funded cases. Participants were recruited to the study via an online support group as well as charities. Parents were interviewed about their experiences of their child’s diagnosis, treatment and decision-making concerning proton therapy, as well as their post-treatment experiences. Interviews were audio-recorded and transcribed verbatim. The use of Nvivo software was employed to aid analysis of data.

Additionally, discourse analysis of six information documents, related to proton treatment, which are accessed by and made available to UK based paediatric families was conducted. This analysis was carried out in order to reveal the privileged discourse embedded within official accounts and to look at whether and where contrasting views are reflected and reproduced in parents’ accounts.

### 1.6 Structure of the Thesis

This thesis consists of nine chapters. The two opening chapters provide an overview of the literature which has informed this research. The first chapter offers a review of sociological
literature related to chronic illness, in order to identify what it might tell us about childhood cancers in the context of the current study. With parents at the forefront of this study, the second literature review chapter is focused on literature related to experiences of parenting in the context of childhood illnesses. Following this, Chapter Four outlines the methodological approach and the rationale underpinning decisions to adopt these approaches, the process involved in conducting this study are also detailed.

Four chapters comprise the report on findings of the research. Chapter Five is a discourse analysis of patient information documents which are accessed by and made available to UK based paediatric families, preparing for treatment and travel to the proton centres abroad. The aim of this is to reveal the privileged discourse embedded within the official accounts and to provide a basis to compare to parents’ accounts. Three themes organise this document analysis chapter; the discourse of proton therapy, the notion of parents and the way they are positioned and situated within their child’s experience of treatment, and gaps and anomalies. In Chapter Six, parents’ understandings of proton therapy and their approaches and preferences towards treatment decision-making are examined. Additionally, the different treatment pathways involved in these families’ access to proton therapy is outlined. Following this, Chapter Seven, entitled ‘Navigating the Child’s Illness and Proton Treatment Through Parental Expertise’, examines these parents’ knowledge through the lens of expertise. The types of expertise that parents were found to possess, and factors motivating their acquisition of expertise in relation to their child’s condition are explored. The final chapter, Chapter Eight looks at post-treatment experiences and the notion of recovery following proton treatment. This chapter offers insight into the child’s process of recovery from the perspective of their parent(s), whilst also drawing attention to the impact of the child’s illness on their parents and close family members. Finally,
Chapter Nine draws together the main findings of the study and the overall contributions towards wider sociological knowledge.
Chapter 2 : Literature Review, Part One: Experiences and Management of Chronic Illnesses

2.1 Introduction

Advances made in the detection, diagnostic and treatment capabilities of modern medicine have led to disease patterns increasingly moving away from acute diseases, where chronic illness has emerged as a key aspect of modern life. Some diseases which were once categorised as acute are now labelled as chronic; prostate cancer (Bell and Kazanjian 2011) and childhood cancers (Brown 2006, Dixon-Woods et al. 2005, Stewart and Mishel 2000) are examples of such. The majority of paediatric patients involved in this research underwent proton treatment in order to treat a cancerous tumour. This chapter explores the sociological literature related to chronic illness and experiences of illness in general, to identify what it might tell us about childhood cancers in the context of the current study. Literature describing children’s experiences of chronic illness is scant, therefore this literature review has largely drawn from research detailing adults’ experiences. The different aspects of chronic illness experience and management are explored in order to understand some of the features and concerns faced by parents, in relation to their child’s experience of illness and treatment.

This literature review chapter is formed of six parts. The opening segment looks at the concept of biographical disruption, introduced by Bury (1982) and, often adopted as a framework to detail the disruptive experiences of chronic illness. Following this, section 2.3 examines the concept of recovery from illness, where recovery is conceptualised as a complex and
transformative experience comprised of different components, and not only limited to the physical aspects of illness. It is highlighted that sociological scholarship has largely focused on the individualistic nature of recovery, where experiences and views of carers and the patient’s close significant others have been overlooked. With uncertainty as a central feature of experiences of illness, especially chronic illness, section 2.4 provides an overview of the literature related to uncertainty. In this section, the contribution of medical technologies to expression of these uncertainties are highlighted, where the role of socio-cultural contexts becomes significant. Leading on from this, section 2.5 examines the meanings and understandings attached to medical technologies. With Proton Beam Therapy a central feature of this research, it is important to explore factors which might contribute towards views and expectations of treatment technologies, which consequently shape approaches towards decision-making. In section 2.6 decision-making involving treatments and self-care is examined, with reference to the patient and clinician encounter. With the prevalence of chronic disease, patients are increasingly encouraged to take charge of their illness and to evaluate for themselves the benefits and risks of their different treatment options. In the closing segment of this chapter, patient expertise as a response to chronic illness is explored; Collins’ (2014) framework of expertise as a useful model for understanding different forms of expertise is outlined.

With the majority of paediatric patients involved in this research having been diagnosed and treated for a cancerous tumour, given that proton therapy is largely utilised in the treatment of rare cancers, this literature review has aimed to draw from research related to experiences of cancer, where possible.
2.2 Biographical Disruption

Biographical disruption is a key concept underpinning research related to chronic illness. Developed by Bury (1982), biographical disruption suggests that the “structures of everyday life and forms of knowledge which underpin them” are undermined and disrupted with the onset of chronic illness (p169). Three aspects to this disruption are noted: firstly, taken-for-granted behaviours and assumptions are disrupted, as are explanatory systems used by people; the disruption brought to the latter is described by Bury as so profound that it leads to a fundamental re-appraisal of a person’s biography and notion of self-concept. Third and final, in response to this disruption resources are mobilised and employed by the person. The onset of biographical disruption occasioned by the development of chronic illness is thought to represent an assault on the person’s physical self, as well as their identity (Bury 1991, Charmaz 1983).

Biographical disruption has been used as a conceptual framework to analyse a multitude of chronic conditions. However, Williams (2000) has argued that it cannot be used as an umbrella concept applicable to all experiences of chronic illness; this had led to recent amendments to the theory. Taking stock of context and timing of the illness, Williams suggests that some people may experience chronic illness as biographical continuity, rather than change and disruption. Using the example of children who have lived with a condition from birth Williams asserts that whilst the lives of these children no doubt appears disrupted, in comparison to socially-set standards and perceptions of normality, existentially speaking these children’s biographies have not necessarily shifted; ‘continuity rather than change’ remains the guiding principle of their experiences (ibid, p50). Most recently, this has been challenged by Bray and colleagues (2014) who suggest that children, and their parents, can experience diverse and
changing experiences associated with chronic condition management, which do not always reflect the concept of disruption and continuity; this is explored further in the next chapter. A further criticism of biographical disruption, from Faircloth and colleagues (2004), is for its failure to take account of mitigating circumstances and assuming that illness will always present a person with an intense crisis. Their research, which involved individuals who had experienced a stroke, found older stroke sufferers to be accepting of this illness since they viewed it as a normal and expected aspect of their biography; here illness is understood as biographical flow (Faircloth et al. 2004). With a focus on children and young people, Monaghan and Gabe (2015) looked at experiences involving asthma. Using the concept of biographical contingency, the varied ways asthma presents itself and impacts the illness experience is highlighted. For example, children involved in their study suggested that their illness is ‘only sometimes’ a problem, dependent on the type and severity of the symptoms they experience.

Limited research based on children’s experiences of chronic illness is available (see Monaghan and Gabe 2015, Atkin and Ahmad 2001 for examples), but the majority of biographical research has predominantly looked at conditions managed during adulthood (see Locock et al. 2009, Wilson 2007 and Faircloth et al. 2004 for examples). Wilson’s (2007) research involving women diagnosed with HIV infection highlights the threat of this disease on mothers’ identities. Recognising the fatal threat of HIV on their identity as a mother, participants in the study placed great emphasis on establishing and maintaining their pre-existing identity as a good mother towards their children. This study draws attention to the fact that respondents did not view their condition and its implications in individualistic terms (Wilson 2007). Elsewhere, Bell and colleagues (2016) have examined the experiences of people living with Meniere
disease⁴, and their close family members, from the patient’s perspective in order to look at how experiences of chronic illness can be closely entwined with and shaped by experiences of ‘linked others’. In their study, participants with young children spoke of the adverse impact of symptoms on their ability to fulfil their desired parental role and reflected on the effect of this on their relationship with their children. Concerns about the impact of intensifying symptoms on the family were mentioned, where in one example the onset and progression of symptoms had hindered a participant’s ability to work, as she had done prior to the onset of the condition, which affected her ability to look after her family and also placed significant strain on her partner. These studies highlight the way experiences of chronic illness, whilst disrupting and heightening the sufferers’ sense of vulnerability, can also be extended to and impact the lives of close family members.

Some biographical research has examined experiences from an alternative perspective. Studies have looked at parents’ experiences involving their child’s mental health illnesses, suicide and cancer, although this is limited (see Owens et al. 2008, Hardern 2005, and Young et al. 2002 for examples). With a focus on mothers’ experiences involving their child’s cancer, Young and colleagues, suggest that although mothers are not ill themselves, they experience many of the consequences of chronic illness, such as biographical disruption, compromise in role function and deterioration in quality-of-life (2002, 2002a). The studies draw attention to the disruption that a child’s illness can bring to parents’ lives and illustrate the importance of recognising aspects related to chronic illness when examining the experiences of parents involved in the care and management of their child’s illness. The focus of this thesis is on parents’ experiences involving their child’s illness and proton treatment. It is anticipated that the disruptions

⁴ Meniere disease: A condition of the inner ear that causes sudden attacks of vertigo, tinnitus, ear pressure and hearing loss (NHS 2017)
pertaining to these parents’ lives may be heightened due to the travel element involved in accessing proton treatment for their sick child.

The next section is focused on recovery. Whilst advancements in medical technologies have led to improved mortality rates and long-term survivorship for many diseases, such as childhood cancers, the risk of disease recurrence and a range of post-treatment side effects often blurs the meaning of recovery.

### 2.3 Recovery

Research examining experiences of recovery from illness is scarce, and a well-rounded literature and conceptual framework for recovery is absent. The available research is primarily based on adults’ experiences, where studies of biographical disruption are entwined. Recovery from illness typically refers to a return to normal and re-establishing of the pre-illness status quo (Parsons et al. 2008). As a process, recovery has been described as “the overcoming of disease, the working through of illness experience and the transition back from the status of sick person to that of healthy individual” (Radley and Taylor 2003, p130). Whilst this notion of recovery may be achievable for some illnesses and ailments, fitting within this framework of recovery is more problematic for other conditions. For patients treated for cancer for example it is unlikely that they fully achieve this sense of recovery, since treatment related side effects and the risk of cancer recurring can bar patients from ever feeling fully recovered (Bell and Kazanjian 2011). According to Foster and Fenlon (2011), whilst many people are now living longer after their cancer diagnosis, disease free, many of them end up with a health profile similar to people living with a long-term condition. Medical technologies and knowledge play a role towards this unachievable ‘recovered’ status, where continued medical
screenings and an array of possibilities and risk situations makes definitive judgments about health statuses difficult (Bell and Kazanjian 2011, Frank 1991).

Elsewhere in the literature, recovery has been described as a complex and transformative experience, based on the patient’s personal values and goals (Grant et al. 2009, Godfrey and Townsend 2008), and not solely dependent on functional and physical abilities. Recovery is conceptualised as the ability to re-establish the continuity of selves and the maintenance and preservation of roles and relationships, in face of change (Foster and Fenlon 2011, Grant et al. 2009, Godfrey and Townsend 2008). Research carried out by Grant and colleagues (2009), exploring the process of recovery following Total Hip Replacement (THR), found the process of recovery from surgery to not only be physical. Having reclaimed their physical abilities, participants to their study also set out to re-establish their roles and relationships within their home, community and society, which had been compromised as a result of their ailment. Recovery is therefore conceptualised as being comprised of distinct, but interrelated processes; physical, psychological and social. Godfrey and Townsend (2008) found several factors which shape the meaning and process of recovery, in later life; prior circumstances, illness onset and trajectory, comorbid health problems and cumulative loss in older age. In their study, individuals experiencing the same type of illness did not conceive of recovery in the same way.

Recovery is subjective and can mean different things to different people, and is largely dependent on circumstances prior to the illness (Balmer et al. 2015, Foster and Fenlon 2011, Godfrey and Townsend 2008). Faircloth and colleagues coined the term ‘biographical flow’ as way of describing and understanding patients’ narratives of stroke recovery. According to Faircloth et al. (2004) the significance of the illness and how it is experienced and managed depends on a host of issues related to the person’s biography. Elsewhere, drawing on the
chronic illness research, and the assumption that cancer survivors will need and want to rebuild their lives and identity (Bury 1982, Charmaz 1983), Foster and Fenlon (2011) suggest that diminished confidence leaves some people ill-equipped to do so; they identify the process of ‘building confidence’ as a key part of recovery.

Foster and Fenlon (2011) examined adult cancer patients’ recovery and self-management, following completion of primary cancer treatment. The post-treatment accounts of these patients were found to not just be limited to physical consequences and the psychological distress of diagnosis and treatment, but also concerned with reclaiming and rebuilding their pre-diagnosis lives and identities. According to Foster and Fenlon, having the support to rebuild lost confidence is a key part of recovery, for if these patients regain their confidence, they will then be in a better position to manage their problems and recovery of their health and well-being (2011). Elsewhere, Balmer and colleagues (2015) allude to the range of physical, psychological and social disruption brought about by the onset of cancer. Achieving a full sense of recovery is thought to be difficult, or in fact impossible, for cancer patients since such diagnoses continue to threaten biographical trajectories and self-identity forever. Echoing similar findings to Foster and Fenlon (2011), Balmer and colleagues (2015) found that participants valued the ability to return to normal or at least maintain some level of normality; however, where health complications made engagement with a prior-self impossible a changed or new normal was accepted.

In experiences of illness, normalisation is employed in order to re-establish a sense of normality following from disruption brought about by diagnosis (Locock et al. 2009); Locock and colleagues termed this biographical repair. Normalisation is defined as attempts which serve to maintain a normal life and sustain qualities that make up who people are (Weiner 1975 in
Chapter 2: Literature Review, Part One: Experiences and Management of Chronic Illnesses

Sanderson et al. (2011, p619). Researching the experiences of young people living and coping with sickle cell disorder or thalassaemia major, Atkin and Ahmad (2001) found that they adopted various coping strategies to live and achieve a ‘normal life’ and maintain a positive identity. Normalcy was sustained by these youngsters comparing themselves to children with other chronic illnesses, including those who were worse off than themselves. However, the seriousness of the condition and uncertainties made these coping strategies vulnerable; even when the condition was stable, worries about the future remained (Atkin and Ahmad 2001). These uncertainties were in tension with the sense of normality that these patients worked hard to achieve. The next section will look at uncertainty, a core theme of chronic illness.

Of the limited literature on recovery from illness, the majority of research is based on an individualistic adult patient perspective, where recovery from the perspective of children and young people is scarce. Additionally, research examining the meaning of recovery from the perspective of a carer or patients’ significant other(s) is absent. Whilst this study does not have access to the voice of the young patients, it will look at the ways parents understand and form views of their child’s recovery, following proton treatment for a tumour. This research presents an opportunity to explore what recovery might mean in the context of the experiences of paediatric cancers and rare tumours, an often-overlooked group of patients in the literature. The following research question is therefore posed; ‘How do parents understand and form views of their child’s recovery, following proton treatment for a cancerous or benign tumour?’. Given that PBT is largely pitched based on its abilities to reduce side effects and improve patients’ quality-of-life, it will be interesting to see whether this group of patients’ post-treatment experiences are different to other cancer patients.
Chapter 2: Literature Review, Part One: Experiences and Management of Chronic Illnesses

The earlier discussion in this chapter also highlighted the fact that experiences of chronic illness are not individualistic and are in fact interwoven within wider family contexts. Some research has highlighted the impact of a child’s illness on their parents, where the focus has often been on mothers. With the aim of also including the voices of fathers, this research will look at what recovery might mean for parents, whose child has undergone proton treatment for a tumour. The following research question is framed; ‘How do parents speak of their own recovery, following their child’s experience of proton treatment?’

Whilst looking at the recovery of health and well-being, this research will also look at recovery to mean a return to normal and/or preservations of normality.

2.4 Uncertainty

Uncertainty is central to experiences of cancer survivorship, and chronic illnesses (Parry 2003). Underpinning Bury’s (1982) study of biographical disruption are the uncertainties experienced by the patient, where for example they cannot be certain about how their illness will unfold in the future. Adamson (1997) distinguishes between two forms of uncertainty within medical sociology: existential and clinical. Existential uncertainties are individualistic, private and part of the illness experience. In Adamson’s own words, “existential uncertainty is that form of uncertainty which is experienced privately by the individual patient upon the realisation that the future life of his or her mind, body, and self is in jeopardy” (p134). Clinical uncertainties are described as the gaps in medical knowledge; the realisation by the medical professional that the knowledge necessary to diagnosis and predict an outcome are absent. According to Adamson (ibid), these two forms of uncertainty can operate independently, yet also mutually influence one another and shape the nature of the medical encounter and experience.
Uncertainty from the patient perspective has been studied extensively. Uncertainty has been examined from the experience of people with Irritable Bowel Syndrome (Adamson 1997), chronic back pain (Lillrank 2003), Fibromyalgia Syndrome (Madden and Sim 2006) and Endometriosis (Denny 2009). Women diagnosed with Endometriosis reportedly confront a myriad of uncertainties related to diagnosis, the course of disease and future outcome; both clinical and existential forms of uncertainty inform their experiences. Uncertainty is also common to the experiences of cancer patients. Roberts and Clarke’s (2009) study involving women diagnosed with gynecological cancers found that, one-year post-treatment, the fear of cancer recurrence remained and influenced these women and their partner’s perceptions of the future. Similarly, Parry’s (2003) research on long-term survivors of childhood cancer, also found that uncertainty is largely integrated into their worldview and sense of self.

A focus of my research is to examine the types of uncertainties faced by parents of children treated with PBT, for a type of tumour. Parents’ experiences of uncertainty in the context of childhood illnesses have been explored (Stewart and Mishel 2000, Cohen 1995). According to Cohen, uncertainties involved in a child’s cancer can give rise to parental uncertainty, where she likens this to a second type of chronic condition, situated within and dependent on the first. Based on her research, even when a child’s disease is in a stable condition, certain triggers can heighten and give rise to parents’ uncertainties about their child’s survival; doctors’ appointments, changes in therapeutic procedures and negative discourse and outcomes are examples of such triggers (Cohen 1995). A common thread to parents’ accounts is the uncertainties pertaining to future projections and unfolding of the disease and illness trajectories, with some alluding to the stress involved in diagnostic uncertainties (Cohen 1995).
Uncertainty has also garnered wide interest in the realm of the sociology of diagnosis (Olson and Abeysinghe 2014). Diagnoses legitimise illness, offer an explanatory framework and consequently guides medical care by enabling access to treatment (Jutel and Nettleton 2011, Jutel 2009). When a diagnosis is not given this can lead to undue stress and uncertainty. Lillrank (2003) for example highlights the uncertainties experienced as a result of not receiving a diagnosis in women with back pain, and Madden and Sim (2006) highlight the problematic route involved in reaching a diagnosis for Fibromyalgia syndrome. For these groups of patients, the uncertainties involving diagnosis could be very stressful. It is suggested that uncertainty amongst those with persistent and unexplained symptoms can lead to doubt towards the medical profession (Nettleton 2006). The role of technology within diagnostic uncertainties is paramount. Diagnostic technologies function to reveal and represent the site of disease and legitimise the patient’s complaint (Blaxter 2009, Rhodes et al. 1999), by providing coherence to a set of symptoms and bodily features (Gardner et al. 2011). When tests results prove inconclusive or out of line with the patient and clinician’s expectations, this can lead to uncertainty (Gardner et al. 2011, Jutel 2011, Blaxter 2009). In a closely related area of study, Reed et al. (2016) examined pregnant women’s views on MRI (Magnetic Resonance Imaging). Whilst MRI is often perceived as a technology which offers certainty and truth, Reed and colleagues found that it also became a source of uncertainty for these women. The authors suggest that that some of these feelings of uncertainty were related to popular understandings of MRI, where these women often associated the technology with certain forms of clinical practice, such as the detection of serious disease and cancer. Their research raises important issues related to socio-cultural context of medical technologies and the influence of this on clinical uncertainties.
Technology related uncertainties are not just limited to diagnostic tools. Parry (2003) and Cohen (1995) have both suggested that treatment technologies also act as a source of uncertainty. According to Parry (2003), whilst advancements in medical technologies have led to improved long-term survivorship in childhood diseases, poor understanding about physiological and psychological sequelae and unknown elements about this group of patients’ future quality-of-life has created room for uncertainties. These kinds of uncertainties arguably sit within the realm of clinical uncertainties, described by Adamson (1997). Proton therapy is a novel mode of therapy and is not widely recognised as a type of treatment; its use as a mode of therapy has only recently garnered momentum. Additionally, in comparison to conventional radiotherapy and other forms of cancer treatment, there is a lack of long-term evidence about its use and efficacy. Uncertainty is a key feature of experiences involving in cancer, and parents’ uncertainties involving their child’s experiences of cancer have been documented in the literature; although, experiences of uncertainty pertaining to treatment technologies have received lesser attention. In this research the role of proton therapy as a possible source of uncertainty will be examined. Whilst addressing the broader question of, ‘What uncertainties do parents face in relation to their child’s experience of illness?’, this study will also address the following research question; ‘What uncertainties do parents face in relation to Proton Beam Therapy?’

With a focus on proton therapy, the common denominator in these parent’s accounts, the next section looks at the meanings attached to medical technologies and the implications of this.
2.5 Meanings and Understandings Attached to Medicine and Medical Technologies

Medical technologies broadly refer to diagnostic and therapeutic technologies. The section above briefly alluded to the socio-cultural context of technologies, and their role within shaping experiences of medical uncertainties. Reed and colleagues (2016) found that the MRI acted as a source of both certainties and uncertainties for pregnant women. Whilst participants to their study hoped the MRI would reveal important diagnostic information about their unborn baby’s health, they also expressed reservations towards the use of the technology, based on the popular association of this technology with cancer detection. The authors call for more research to examine the way socio-cultural contexts that technologies operate within effect patient and professional experiences of uncertainty.

That technologies do not operate in a vacuum and are in fact embedded within wider socio-cultural relationships, is not a new concept. The role of practical circumstances, culture, and the socio-political environments in shaping and even creating the sense and significance of systems and artefacts has been noted (Heath et al. 2003, Timmermans and Berg 2003). Timmermans and Berg (2003) usefully review and summarise sociological scholarship related to medical technologies and suggest that traditional medical sociological writings have either overestimated the power and influence of technology in shaping society, or have underestimated the significance of their role, viewing them as basic tools to be socially situated. Categorising these approaches into technological determinism and social essentialism, Timmermans and Berg (2003) suggest that these approaches essentially separate technology from people. They therefore propose the technology-in-practice model, which holds that social interests shape technologies throughout their design and usage, and, in turn, technologies shape
the activation of different social constituencies. Rooted within ANT (Actor network Theory), an approach in science studies which views technology and human as both having agency, the technology-in-practice view speculates that technology might do things, but the ‘what’ and ‘how’ are open empirical questions.

Research has examined cultural beliefs and understandings that medicine and medical treatments are embedded within, and the way in which these shape people’s expectations of their operation and efficacy (Bell 2009, Webster et al. 2009, Moerman 2002). Moerman’s work on the placebo effect demonstrates that in the absence of evidence and experience there is much known about medicine, where this knowledge stems from an overarching cultural model which dictates meaning. To quote Moerman (2002), “much of our knowledge of the world is not an elicitation of what ‘is’, but rather it is a construction laid atop the world of experience” (p67). Bell’s (2009) study on cancer patients’ perception of chemotherapy and the meanings they assign to their treatment reveals two variations; a cultural model and a biomedical understanding of treatment. The cultural model diverges significantly from the biomedical model, where for example it emphasizes the value of suffering as a means of tracking the effectiveness of treatment. Similar to Reed et al. (2016), who highlight the influence of socio-cultural factors in influencing notions of uncertainty related to a said technology, Bell (2009) draws attention to the social-cultural context that prefigures chemotherapy, and which consequently shapes expectations of its use and efficacy as a treatment. Bell notes that chemotherapy is culturally charged and medically prefigured as a type of treatment which induces suffering. For many patients in her study, this suffering was meaningfully transformed into evidence of efficacy; patients experiencing side effects interpreted this as visible evidence that treatment is working. For patients who did not experience side effects, the lack of suffering could be interpreted as a cause for concern. Bell concludes that such ill-informed notions
results in implications for the patient such as unnecessary anxiety and stress regarding the actual facts of treatment, which in turn, impact their behaviour towards it (2009). Given that PBT has only recently emerged as a mode of cancer treatment and is relatively unknown, compared to standard radiation and chemotherapy, it is not known how users of this treatment perceive proton therapy and what expectations they have of treatment.

It also follows that not only the content of medicine, but also the form of medicine, such as their colours, shape, amount, size and form of delivery influence the medical experience and attitudes towards medicine (Moerman 2002). For example, it is suggested that patients expect larger pills to work better over middle-sized pills, or red pills to work better than blue pills at treating pains. Furthermore, not only the shape and form of medication and treatment, but the name of medicines encourage patients to perceive medicines in a certain way (Abel and Glinert 2008). In their study which looked at cancer related medication names, Abel and Glinert found that drug names containing high a frequency of sounds associated with smallness and fastness encourages patients to perceive the drugs as fast acting. Their study raises important questions about the possible role of the names of medications in the experiences of cancer patients, especially given the emotionally and culturally charged nature of the disease (Abel and Glinert 2008).

According to a recent study published by ASTRO (American Society for Radiation Oncology 2017), radiation therapy is often feared and misunderstood; especially since the term ‘radiation’ is not a word associated with healing and often invokes fears of toxicity. In fact, radiation treatment is largely preceded by misconceptions, as such that cancer awareness and support organisations, such as BreastCancer.org and CancerCentre.com, have a section allocated to radiation myths and mysteries on their websites; fear of becoming radioactive and toxic is
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commonly discussed in these sections (BreastCancer.org 2016 and CancerCentre.com 2017). Public awareness of radiotherapy is limited, and cancer patients are reported to have varying levels of understanding of radiation (Woodman 2013, Halkett et al. 2012, 2005 and Owens et al. 2003). Halkett and colleagues (2012) report that despite the wide use of radiotherapy in treating breast cancer, women in their study knew little about the facts and experience of treatment. In an effort to reduce their fears about radiation therapy, these women tried to prepare themselves by relying on different information sources. Whilst a cancer diagnosis alone induced anxiety, uncertainties, poor knowledge and misconceptions about radiotherapy are thought to further heighten these anxieties and influence patient decision-making (Williams et al. 2017 and Halkett et al. 2012, Owens et al. 2003). These concerns are extended to paediatric patients and their parents, where Woodman (2013) suggests that parents of children diagnosed with CNS (Central Nervous System) tumours often attend the initial consultation with preconceived expectations and ideas about the disease and treatments involved; some of these may be ill-informed and based on wider discourses present in society. According to their findings, parents of CNS paediatric patients often perceived radiation therapy as a very aggressive mode of therapy associated with complex physical and neurocognitive sequelae and are therefore often severely anxious and daunted by the process and potential side effects of treatment (Woodman 2013).

Proton Beam Therapy is a type of radiation therapy, however given that the name of this treatment makes no reference to its radiation nature patients may view this treatment differently and have different expectations regarding its outcome and efficacy, which may also affect their attitudes towards decision-making. This research will look at, ‘How do parents view and understand Proton Beam Therapy?’ Additionally, this study will also look at how proton therapy is depicted within patient information leaflets and compare findings with parents’
accounts. The following question is posed, ‘How is Proton Beam Therapy depicted in the information leaflets?’

Decision-making is the focus of the next section.

2.6 Decision-Making Involving Treatments and Illness Management

Research examining treatment choices have highlighted a range of non-clinical factors thought to influence these decisions. Husain and colleagues (2008) examined factors influencing older women’s attitudes towards treatment choices for their breast cancer. Whilst the majority of women in their study expressed a passive stance towards treatment related information seeking, and cited their confidence in the medical personnel’s expertise for this, some women disregarded the information relayed to them by the physician and opted for a specific treatment based on their past experience involving breast cancer therapy. One woman requested treatment based on her experience involving a close relative’s diagnosis and treatment, and another woman based this decision on her personal previous experience involving breast cancer treatment. Elsewhere, Kreling et al. (2006) examined breast cancer patients’ attitudes towards chemotherapy and factors influencing their decision to have this treatment and found that some of their participants base their decisions on wider beliefs and expectations about treatment.

Non-clinical factors influencing treatment decision-making are not only limited to patients. Tariman and colleagues’ (2014) research involving adults newly diagnosed with symptomatic myeloma highlights a range of factors considered by both physician and patients in treatment decision-making: these include patient’s personal preference, quality-of-life concerns, family
opinion, insurance and cost, social support considerations, age and convenience. For example, oral chemotherapy was deemed more convenient, both from a patient perspective and from the physician’s perspective, because the oral pill can be taken at home by the patient and therefore results in fewer clinical visits. Fewer visits reduces the burden on healthcare services, whilst also offering older patients more independence and requires less family burden.

In their study, Tariman et al. (2014) also found a level of discordance between patient and physician’s perspective about who the decision maker ought to be. The majority of patients involved in their study perceived the clinician as decision maker, whilst the physicians suggested that the decision is ultimately made by the patient. In order to explain this discordance, the authors suggest that perhaps if the physician had made a strong recommendation for a certain treatment option, and the patients did not feel adequately knowledgeable about the different options, the patients may have chosen to follow the doctor’s recommendation and therefore viewed them as the decision maker. The passive role of patients within decision-making has been noted elsewhere, where it is suggested that their complacency with this stance is based on the view that such medical decisions require expertise and clinical experience, which only the clinicians possess (Husain et al. 2008, Charles et al. 1998).

Treatment decision-making and the physician-patient encounter have been conceptualised as a spectrum, with the paternalistic physician as perfect agent model at one end and the informed treatment decision-making model at the other end (Gafni et al. 1998 and Charles et al. 1997). Based on a view which assumes a passive role for patients, the first model assumes that the patient delegates authority to the doctor to make treatment decisions for them. This type of relation is justified based on the assumption that the doctor possesses the necessary knowledge and skill needed to make a treatment decision, based on their scientific training and expertise,
without consideration for the patient’s preferences. In the informed treatment decision-making model, the physician transfers the technical and scientific expertise to the patient, so that the s/he can make an informed decision based on their own preferences and best scientific knowledge. Yet this model is not straightforward and the challenge here is to ensure the doctor shares and transfers knowledge in an unbiased way. Overall however, it is suggested that patients’ actual preferences for the role they want to play in the decision-making process are neither uniform nor stable. Using the literature on cancer, Gafni et al. (1998) suggest that whilst most patients have high preferences for information about disease, treatment alternatives and prognosis, their preference for participation in decision-making is varied.

The varied preferences of patient involvement in decision-making have been reported elsewhere, where these are thought to be context dependent (Eliacin et al. 2015, Say et al. 2006, Thorne et al. 2003). In their literature review of quantitative and qualitative studies examining factors influencing patients’ preferences, Say and colleagues (2006) highlight a number of factors found to influence patients’ preferences in decision-making involvement; these include, the patient’s experience of illness and medical care, their diagnosis, the type of decision they have to make, the knowledge they have acquired about their condition, their attitude towards involvement, their experiences involving interaction with healthcare professionals, as well as demographic variables, such as sex and education. People with higher education were found to prefer a more active involvement for instance, and where the decision concerned a minor illness patients have shown more interest and willing to be involved, as opposed to a situation involving a more serious physical ailment. It is noted however that these preferences evolve over time and as the person progresses in their illness trajectory. This issue is also raised by Thorne et al. (2003), where their study involving HIV/AIDS, Multiple
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Sclerosis and diabetic patients’ decision-making involving self-care alludes to the evolving nature of these patients’ preferences and approaches.

Highlighting the complex nature of self-care decision-making, Thorne and colleagues (2003) draw attention to the variety of resources that chronic patients draw upon in order to manage and make decisions. With a commitment to not being controlled by their disease, these patients drew on their awareness of their responsibility to self, past experiences and the credible accounts of others, in order to take charge of their lives. Characteristic of this decision to assume control was an intensified learning about the disease, treatment, and their body’s unique response to interventions and situations. Acquisition of this knowledge relied on sources of information such as healthcare professionals and other people diagnosed with the disease; support groups served as a valued source of information, especially at the point of diagnosis. The HIV/AIDS group of patients largely viewed themselves as an important source of new information for their doctors and tasked themselves with keeping up to date with medical developments, suggesting that doctors cannot possibly keep up with all there is to know on the topic (Thorne et al. 2003). Suggestion of an in-depth level of knowledge acquisition is reported by Kreling et al. (2006) in their study, where a participant explained that they had done a lot of homework about their disease and its treatment, and described themselves as both surgeon and oncologist. However, whilst these patients task themselves with acquiring as much information as possible and believed they had the right to participate in decisions concerning their treatment plan, there still remains a degree of variation towards their preferences based on their beliefs about the role of the clinician. In Kreling and colleagues’ study (2006), participants spoke of their struggle to deal with the vast amount of overwhelming information, whilst the majority of HIV/AIDS patients involved in Throne and colleagues’ (2003) review suggested that in spite of their research, they were still more likely to seek competent expert
advice. Research examining patients’ views and attitudes towards decision-making involving radiation therapy also found that these patients relied on information imparted by their clinicians and sourced from information leaflets in order to learn about the treatment (Halkett et al. 2005, Owens et al. 2003).

This research is interested in examining the way parents approach and manage decision-making involving a new type of therapy, i.e. Proton Beam Therapy. The subsections above highlighted the range of factors which influence users’ perceptions of treatment and attitudes towards decision-making. Proton therapy is a new type of treatment and it is not known how users of the treatment perceive the treatment and how they approach decision-making involving this treatment. For instance, it is not known what sources of information, experience and discourse they draw from and model their views of treatment on. With these questions in mind, the research is set to address the following research question: ‘How do parents manage decision-making involving Proton Beam Therapy?’

In the following section, the notion of expert patient as a response to chronic illness is examined. With disease patterns increasingly shifting towards the prevalence of chronic diseases, patients are increasingly encouraged and expected take charge of their illness and to evaluate the benefits and risks of different treatment options (Prior 2003 and Holman and Lorig 2000).

2.7 Patient Expertise

The rise in chronic illnesses over the past decades has given rise to healthcare policies which foster self-care and promote greater patient involvement in decisions concerning their
healthcare (Lindsay & Vrijhoef 2009, Prior 2003). Such initiatives are thought to encourage patient responsibility and empowerment, whilst also relieving financial burdens to wider healthcare systems (Seear 2009). This has given rise to the notion of ‘expert patient’, evident within UK policy. ‘The Expert Patient’ (DoH 2001) is a policy initiative which values the knowledge and experience of patients and encourages them to become key decision-makers in their treatment process, and take on more control and autonomy. Access to and the growth in web-based health related information has also supported the creation of expert patients, since consumers are now able to thoroughly research their conditions and make decisions about their treatment and illness management (Nettleton 2013, Nettleton 2004, Henwood et al. 2003). Cultural messages encouraging patients to take on a more active role in their health care, and the widespread use and access to information has led to the felt imperative to become an expert and critical patient (Stacey et al. 2009, Ziebland 2004).

Overall, increasingly easy access to health-related information, which was once assumed to be only accessible to the medical profession (Nettleton 2013), and the emphasis on patient empowerment and shared decision-making has resulted in changes to the nature of the clinical encounter, where the power imbalance between doctor and patient has shifted (Dimond 2013, Nettleton 2004). In Nettleton’s words, “the professional-patient relationship, once characterised as a meeting between the knowledgeable expert and the ignorant lay person, is now more appropriately, and more accurately, described as a ‘meeting between experts’” (Nettleton 2013, p123).

The interest in patient expertise has seeped into the realm of medical sociology, where the notion of an ‘expert patient’ or ‘lay expert’ has been largely studied, although there is no consensus on what actually constitutes ‘expertise’. The literature on lay expertise has been
organised by Prior (2003) into three themes; Firstly, lay expertise has been formulated as expertise acquired by virtue of experience, where first-hand experience of a condition provides patients with a unique understanding of their body and how to manage their condition (see Seear 2009, Peterson 2006, Fox et al. 2005 for examples). Peterson’s study involving individuals with various genetic conditions found them to be in procession of considerable technical knowledge about their condition, its treatment and management; where they were also able to use scientific terminology to describe these. In other instances, lay expertise has been given the same credence as scientific expertise (see Schaffer 2007, Epstein 1995, Arksey 1994 for examples). Schaffer’s study involving mothers of children with genetic disorders highlights their role as co-producers of knowledge, where their experiential knowledge contributes to and shifts the boundaries of what constitutes authoritative knowledge (2007). The third and final theme, noted by Prior, conceptualises lay expertise as an outcome of social groups (see Jenkins 2014, Brown et al. 2004, Rabeharisoa, 2003 for examples). Rabeharisoa’s research, which is based on the French Muscular Dystrophy Organisation, has highlighted the scientific activism of patient groups and their ability to steer research orientations for example. Despite this plethora of literature, the notion of lay expert remains problematic in Prior’s view, especially since it is not clear how exactly lay people might qualify as expert.

Drawing from his own research, Prior (2003) demonstrates that patients may become experts on their own bodies, yet this expertise is limited and confined to their own body and their own case, and does not necessarily reflect the full scope of the illness. Furthermore, Prior’s research also shows how carers may also become experts, but their expertise too is limited and confined to what is experienced; “what is not experienced is not known” (Prior 2003, p48). In Prior’s view, and other scholars alike, experience alone does not qualify expertise. To qualify as an expert, in depth knowledge and expertise of the subject matter and the relevant qualifications
are necessarily (Prior 2003). The notion of expert patient is problematic since it undermines the structural power and qualifications which set aside experts from the ordinary (Fox et al. 2005, Prior 2003). The term expert ought to be reserved for those who have undergone extensive training and possess a high degree of skill and knowledge in a certain area (Wilson 2001) and have attained the relevant qualification and license to practice (Prior 2003). It is therefore evident that there is need to clarify what constitutes ‘expert’ in the realm of sociological scholarship related to health and illness. Collins’ (2014) framework of expertise is helpful in better understanding and conceptualising expertise; his framework applies to the general concept of expertise.

According to Collins (2014), we all possess a range of everyday expertise which we have acquired without putting any self-conscious effort; this is ubiquitous expertises. Speaking in our native tongue or knowing table manners are examples of ubiquitous expertises. This is different to specialist expertises, acquisition of which requires a little more effort and forms of training. The third kind of expertise is meta-expertises; the type of expertise which is used to judge and discern between others’ expertise. The following table, Table 4, outlines these three different expertises.

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5 Collins refers to ‘expertises’ throughout his book in order to describe different types of expertise.
Table 4: Table of Expertises. (Source: Collins 2014, p62)

<table>
<thead>
<tr>
<th>1. Ubiquitous Expertises</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Specialist Expertises</td>
</tr>
<tr>
<td>3. Meta-Expertises</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ubiquitous Tacit Knowledge</th>
<th>Specialist Tacit Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beer-mat Knowledge</td>
<td>Interactional expertise</td>
</tr>
<tr>
<td>Popular understanding</td>
<td>Contributory expertise</td>
</tr>
<tr>
<td>Primary source knowledge</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>External (Transmuted expertises)</th>
<th>Internal (Non-transmuted expertises)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ubiquitous discrimination</td>
<td>Technical connoisseurship</td>
</tr>
<tr>
<td>Local discrimination</td>
<td>Downward discrimination</td>
</tr>
<tr>
<td></td>
<td>Referred expertise</td>
</tr>
</tbody>
</table>
In the first row are *ubiquitous expertises*, these are expertises common to a culture and which are learnt through growing up in a society. Regardless of the type of expert one becomes, they will always begin with acquisition of ubiquitous expertises. In the second row is *specialist expertises*; attainment of these requires some level of conscious learning. This second type of expertises has been divided into *ubiquitous tacit knowledge* and *specialist tacit knowledge*. The three forms of ubiquitous tacit knowledge, *beer-mat knowledge*, *popular understanding* and *primary source knowledge* are easier to acquire and more readily accessible, through popular media and wider discourse, as well as non-expert research conducted on the internet or readings of accessible technical literature. The heavy division between primary source knowledge and interactional expertise distinguishes these two types of tacit knowledge, for there is a high gulf between knowledge acquired solely through ubiquitous expertise and that which is based on the acquisition of specialist tacit knowledge.

*Interactional expertise* and *contributory expertise* inform the category of specialist tacit knowledge; according to Collins’ model, these are forms of expertise necessary to be considered an expert. Contributory expertise is developed with practical experience and is likened to an apprenticeship. One becomes a contributory expert by learning from other experts and picking up their skills and techniques. Interactional expertise is acquired by learning and engaging in the spoken discourse of an expert community to the point of fluency, but without participating in the practical activities. To become a specialist expert in a field, extensive training to acquire both contributory expertise and interactional expertise is required.

A further category of interactional expertise also exists, entitled ‘*special interactional expertise*’. Likening this category to people like himself, Collins explains that it constitutes a small and unusual group of specialist experts who, “acquire interactional expertise through
occupying a strange role in which they immerse themselves in the discourse of a specialist 
community without fully participating in that community’s expertise” (Collins 2014, p116). 
Applying this category to himself, Collins is referring to writers and researchers who study the 
practice of other professions.

The third row in Table 4 is allocated to *meta-expertises*, which are related to choosing between 
experts and their expertises. At the far end of this row is *ubiquitous discrimination*, the 
everyday expertise used to make judgment calls and decide whether someone is honest or not. 
To the right of this is *local discrimination*, which is more reliable than ubiquitous 
discrimination for it is based on local and specific inside information. Both ubiquitous 
discrimination and local discrimination are grouped under the header *transmuted expertises*, 
since they use judgments about people and transform them into technical choices. On the other 
hand, *non-transmuted expertises* rely on use of substantial technical expertise, rather than 
expertise about other people. *Referred expertise* is the use and application of expertise from 
one domain to another. *Downward discrimination* happens when a senior specialist makes 
judgment about the claims of a more junior expert within the same field. And finally, *technical 
connoisseurship*, a form of ubiquitous expertise, is based on an understanding of how things 
ought to operate and be. Giving the example of a plumber or tiler, Collins explains that although 
not crafts persons ourselves, we draw from our everyday knowledge of tiles and pipes in order 
to decide whether we think the job has been done correctly.

Collins (2014) framework of expertise is helpful for it provides a framework for examining 
expertise, especially within the contested field of ‘patient expertise’. Drawing from the 
example of chronic disease patients, Collins argues that they are experts by virtue of their 
experiences, where they learn from other patients and doctors about how to manage their
disease, whilst also drawing from their own personal experiences of the illness. Most recently Green (2017) applied Collins’ framework in order to examine the forms of specialist expertise that men treated for prostate cancer possess. These men were found to possess contributory, interactional and special interactional expertise for prostate cancer. Their personal experiences of the illness, interactions with medical practitioners in clinical encounters, as well as their involvement with support groups and interactions with former patients and survivors had contributed towards their acquisition of this expertise (Green 2017).

Whilst parents have been described as experts in the literature, the research which it is situated in is rather descriptive; this literature is summarised in the next chapter (section 3.5.3). Little research has examined the types of expertise that parents of paediatric patients possess, and how they have come to acquire this expertise. This research will apply Collins’ framework of expertise to parents’ accounts involving their child’s illness, in order to examine the types of expertise they possess. The following research question is posed: ‘What types of specialist expertise do parents of children treated with Proton Beam Therapy possess?’

2.8 Conclusion

Advances made in the detection, diagnostic and treatment capabilities of modern medicine have led to disease patterns increasingly moving away from acute diseases, as such that some diseases such as childhood cancers, which were once categorised as acute, are now described as chronic (Brown 2006, Dixon-Woods et al. 2005, Stewart and Mishel 2000). This literature review has highlighted core features of living with and managing chronic illnesses. Biographical disruption, meanings attached to recovery, uncertainty, understandings of
medical technologies and related decision-making, as well as patient expertise have been examined in this chapter.

Although the notion of lay expertise remains contested (Fox et al. 2005, Prior 2003), limited research has demonstrated that chronic illness patients possess forms of specialist expertise related to their condition (Green 2017, Collins 2014). Literature describing parents of paediatric patients as experts is outlined in the next chapter, however this research is largely descriptive. Is it not known what types of expertise parents of paediatric patients possess in relation to their child’s condition, and how they come to acquire such expertise. Using Collins framework of expertise, this research will look at the types of expertise parents of children treated with proton therapy possess. Making use of this framework of expertise addresses concerns raised by scholars regarding the lack of clarification regarding the use and assignment of the term ‘expert’.

Uncertainty is a key feature of cancer survivorship and experiences of chronic illness (Roberts and Clarke 2009, Parry 2003). Uncertainties involved in a child’s illness can give rise to parental uncertainties, where a common thread to parents’ accounts of uncertainties involves future projections and unfolding of the disease (Cohen 1995). The role of novel treatment technologies as a source of uncertainty was identified, where unknown elements about treatment outcome can create room for uncertainty (Parry 2003, Stewart and Mishel 2000, Cohen 1995). Proton therapy is a novel mode of therapy and, in comparison to conventional radiotherapy and other forms of cancer treatment, there is a lack of long-term evidence about its use and efficacy. In this research the role of proton therapy as a possible source of uncertainty will be explored.
Treatment technologies and medicines do not operate in a vacuum, and a whole host of factors including socio-cultural contexts give meaning to and influence users perceptions, expectations and experiences of treatment (Reed et al. 2016, Heath et al. 2003, Timmermans and Berg 2003). Users draw from experiences, wider discourse and popular associations (Bell 2009), as well as information relayed to them by their healthcare professionals in order to formulate their views and make decisions about treatments (Halkett et al. 2012, Owens et al. 2003). Poor knowledge and misunderstandings can create room for uncertainty and influence decision-making (Halkett et al. 2012, Bell 2009, Mathews 2001). Proton therapy has only recently emerged as a mode of treatment and it is not known how users perceive this treatment and approach decision-making about it. Parents of paediatric cancer patients often attend medical consultations with preconceived expectations about treatments, some of which may be ill informed and based on wider discourses present in society (Woodman 2013). With a focus on parents, this research will look at how they manage decision-making involving this new treatment technology and the sources of information they rely on in order to formulate their views and decisions.

Even when a person’s condition is stable, uncertainties about the future and unknown entities about their situation can distort notions of recovery, and efforts on the sufferer’s behalf to instil normality. Recovery is traditionally described as a process involving the overcoming of disease and the transitioning back from the status of sick person to that of healthy individual (Radley and Taylor 2003); however, fitting within this framework of recovery is not achievable for all. Recovery has been described as a complex and multifaceted experience, based on the patient’s values and goals and not solely dependent on physical entities and recovery of health; there are social and psychological entities related to recovery to consider as well (Grant et al. 2009, Godfrey and Townsend 2008). The ability to return to normal, or at least maintain a level of
normality is considered an important element of recovery (Balmer et al. 2015, Foster and Fenlon 2001, Atkin and Ahmad 2001). The limited literature on recovery is based on adult patients’ experiences, where children and young people’s views are scarce. Additionally, research examining the meaning of recovery from the perspective of a carer or patients’ significant other is absent. This research will look at the ways parents understand and form views of their child’s recovery, following proton treatment for a tumour. Given the nature of PBT and its ability to reduce significant side effects, often associated with radiotherapy, it will be interesting to see whether this group of patients’ experiences of recoveries is different to accounts detailed in the literature (Balmer et al. 2015, Bell and Kazanjian 2011). It has been established that experiences of chronic illness are not individualistic and are in fact interwoven within wider family contexts. With this in mind, this research will look at what recovery may mean for the patient’s carer and close significant others.

Most importantly, failure of sociological scholarship related to chronic illness to move beyond an individualistic approach when examining aspects of these experiences was noted in this chapter; where the majority of research is related to adult patient experiences. Research has drawn attention to the way experiences of chronic illness are entwined with the life experiences and trajectories of close family members (Bell et al. 2016, Wilson 2007, Young et al. 2002, 2002a). The focus of this thesis is to explore the experiences of parents involving their child’s illness and proton treatment. With parents at the forefront of this study, the following chapter will explore literature pertaining to parents’ experiences of managing their child’s illness.
Chapter 3: Literature Review, Part Two: Parenting a Sick Child

3.1 Introduction

The focus of this thesis is on the views and experiences of parents whose child has been treated with Proton Beam Therapy (PBT). With parents at the forefront of this study, it is important to situate the study in research exploring their experiences in relation to their child’s health and illness. This chapter examines the literature on parents’ responses to their child’s illness; research examining parents’ responses to a range of childhood illnesses have been included in this literature review.

The opening segment, section 3.2, looks at the cultural construction of parenthood, and the wider discourses which govern parents’ responses and behaviours in the context of their child’s health and illness. Next, parents’ role and experiences in the context of the clinical encounter involving their child are examined. Section 3.4 is focused on parents’ practices and preferences in decision-making involving their child’s treatment and care. Following this, parents’ responses to uncertainties related to their child’s condition, the different sources of information they draw from and rely on in order to manage their child’s illness, including their own parental knowledge, are examined in section 3.5. In section 3.6 the impact of childhood illnesses on parents and siblings are examined. The chapter closes with a summary of key points, and the research questions formulated, in this and the previous chapter, are outlined.
3.2 The Social Construction and Discourses of Parents, in the Context of Childhood Illnesses

It is suggested that the social construction of parenthood is linked to the social construction of childhood in that context. Parental behaviour in response to childhood illnesses is therefore thought to be socially constructed. In Western cultures, the social construction of childhood depicts children as vulnerable and in need of protection, this requires parents to conform and oblige to traditional ideologies of care and to devote themselves selflessly to the welfare of their child (Lupton 2013, McKeever and Miller 2004). Such cultural connotations are especially magnified within the experiences of seriously ill and/or disabled children (Dixon-Woods et al. 2005, McKeever and Miller 2004). In the case of childhood cancer for example, parents of paediatric patients characterise themselves as having a range of obligations which are founded on the dominant discourse of parenting, as well as the discourses surrounding the disease (Dixon-Woods et al. 2003, Young et al. 2002). In their study involving mothers of children with cancer, Young and colleagues (2002) write that the cultural association between cancer and death, coupled with the unpleasant cycles of treatment, heightens parents’ obligations around protection and responsibility towards their child.

Mothers, in particular, are implicit as carers and are expected to conform to principles of intensive parenting, protect their children from harm, promote their health and care for them when they are unwell (Lupton 2013, Maher et al. 2009); these tasks are integral to the maternal labour expected of mothers. To behave otherwise can be viewed as failure to fulfil one’s responsibility as a mother (Lupton and Fenwick 2001), since a healthy child is regarded as the outcome of good maternal work. In the context of children’s experience of health and illness dominant discourse and expectations pervade notion of what constitutes a ‘good’ mother,
where mothers are expected to abide by these codes which stipulate their role and responsibility towards their child (Lupton 2013). Lupton and Fenwick (2001) examined the construction and practice of motherhood in women with hospitalised infants and found that these women draw from two competing views on ‘good motherhood’, their own view and that of the nurses’, whilst practicing motherhood within the constraints of a hospital setting. Whilst mothers emphasized the importance of breastfeeding, physical contact and bonding with their child, the nurses prioritised the mother’s presence in nursery and willingness to learn about their child’s condition and treatment. Nurses would describe a good mother as one who ‘put her child first’ and held certain views and expectations of how mothers ought to behave in the nursery setting. Abdicating from these category-bound qualities could lead to mothers being labelled as ‘difficult’ (Lupton and Fenwick 2001).

Gender expectations also determine and produce social constructions and expectations of what it means to be a father (Chesler and Parry 2001). In the context of childhood illnesses, fathers are socialised to be less active parents, than mothers are, in caretaking activities for example. With fathers expected to focus on employment and their male provider role, mothers are more likely to accompany their child to doctor and hospital appointments, assume a nursing role and be more immersed in their child’s illness (ibid). There are suggestions however that the distribution of parental roles has gradually shifted, and the constructions of fatherhood are changing (Pelchat et al. 2007); with more mothers entering the workforce, fathers have become more involved with caring tasks for their children. However, scholarship has suggested that socio-cultural structures of healthcare systems play a role in shaping gendered patterns of caregiving amongst parents (Jones and Neil-Urban 2003, Chesler and Parry 2001). With a focus on fathers, Jones and Neil-Urban (2003) call for healthcare practitioners and social
workers to aid fathers by recognising and facilitating their role as caregivers and including them in communications and exchanges of information.

Whilst the role of fathers as providers of care has been highlighted, the majority of research examining parental experiences of childhood illnesses is predominantly based on mothers’ accounts. This is perhaps partly due to gender conditioning and social norms which largely result in mothers being more involved as the primary caretaker of children and therefore more involved and accessible as research participants. It may also be due to gender-role bias on part of the researchers which have resulted in them largely targeting and recruiting mothers. In this research effort is made to maximise access to fathers’ accounts involving their child’s experience of illness.

Media depictions of childhood illnesses are also thought to create stereotypes and public expectations towards parents. Dixon-Woods and colleagues (2003) studied accounts of childhood cancer in newspapers and contrasted these with accounts of childhood cancer given by parents during interviews. One of the major findings reported in their study involves the tension which lays between the media depiction of parents and parents’ responses to their child’s cancer. According to Dixon-woods et al. (2003) parents involved in their research talked about a range of quality-of-life impairments but found it difficult to voice these due to prevailing discourses about the duties of parenthood; one example of this is the obligation of proximity, which is the requirement that at least one parent remains close to the sick child at all times. Whilst parents experienced considerable difficulty fulfilling this obligation, Dixon-Woods and colleagues suggest that they appeared keen to assert the adequacy of their parenting by underemphasising the significance of these effects on themselves. According to their report, media accounts promote and feed certain images of childhood cancer and parenthood into the
mainstream which can become a source of tension for parents, for they are at odds with parents’
own accounts and experiences (ibid). The authors of this paper propose that analysis of media
accounts of childhood cancer, whilst offering insight into the construction of childhood and
childhood cancer, can unveil images of appropriate behaviour by parents and expectations of
of texts enables understanding of the cultural component of illness experiences, as well as
ideological dimensions of lay health beliefs and doctor-patient relationships for example; the
approach adopted by Lupton is Discourse Analysis.

Media coverage of the Ashya King case initially depicted his parents as irresponsible adults
who had placed their son’s life in danger, by refusing the doctors’ orders. The tenor of this
coverage shifted however, once it was revealed that the Kings were in search of a ‘better’ mode
of treatment for their son, which had been denied by his primary team of doctors. At the heart
of the media portrayals were assumptions about how parents ought to behave in the context of
their child’s illness. The focus of this thesis is on parents’ experiences involving their child’s
proton treatment. With this in mind, the research will look at information leaflets related to
PBT in order to examine the way parents are portrayed in the context of their child’s illness
and proton treatment, and to see whether these are reproduced in parents’ accounts in the
interviews. The following research question is therefore proposed; ‘What notion of parents is
portrayed across information leaflets?’

The next section looks at the role of parents within their child’s experience of illness and the
clinical encounter.
3.3 The Role and Experiences of Parents in the Clinical Encounter

Parents play a key role within their child’s experiences of illness. They are often the first to recognise that their child is sick and are responsible for taking their child to the doctor (Dixon-Woods et al. 2005), and act as gatekeeper within the clinical encounter by providing information concerning their child’s history and illness (Dimond 2013). In the context of their child’s illness, parents become protectors, decision makers and advocators (Shortman et al. 2013, Woodman 2013, Bluebond-Langner et al. 2007, Hallström et al. 2002). Research has examined the parental role and experience within the context of clinical settings and encounters, and feelings of disempowerment and some role conflicts experienced by parents in these setting have been highlighted (Dimond 2013, Dixon-Woods et al. 2005, Holm et al. 2003, Young et al. 2002a).

Parents take up a significant position in the clinical consultation, especially in cases involving younger children, where they act as gatekeeper and guide to their child and provide information concerning the holistic experience of their child’s illness (Dimond 2013). In some instances, however, the parent(s)’ roles and behaviours can become restricted and instead guided by the clinician; this can sometimes lead to feelings of disempowerment and result in conflict between parents and clinician. Investigating parents’ accounts of their child’s cancer diagnosis, Dixon-Woods and colleagues (2001) found that most parents felt that their credibility as a parent was often challenged by the doctors. These parents spoke of their frustrations when doctors sometimes failed to listen to them and make use of their experiential parental knowledge of what is normal and abnormal for their child. Holm and colleagues (2003) report similar findings, where some of the parents in their study felt like they were being treated in a patronising and disrespectful fashion by the medical professionals during the process of
obtaining a diagnosis for their child. In their study, which examined the way parents participate in the diagnosis and treatment of childhood cancer, Holm et al. (2003) describe parents as ‘advocates’; parents advocate for their child by seeking medical explanations for their symptoms, and by persisting on obtaining a diagnosis. During their child’s treatment phase, parents will advocate for their child by making sure they are informed about their child’s medical status and needs, affirming their child’s medical professionals, limiting medical procedures and taking part in decisions about medical treatment (Holm et al. 2003).

Examining the role of parents of children with cancer within treatment decision-making, Pyke-Grimm et al. (2006) found parents’ sense of responsibility and the overarching expectation that they function as advocates and protectors of their child to play an important role. Some of the mothers involved in their study drew emphasis to the fact that it is their job to make decisions for their child, whilst others alluded to the importance of their parental expertise and the importance of this in treatment decision-making. Echoing a similar view, Hallström and colleagues (2002) also state that parents recognise and acknowledge their sense of responsibility towards their child and therefore wish to be involved in the decision-making process; however, they do not always want to make the final decision and will rely on the medical cohort to help them. Research depicting the way parents approach decision-making for their child is varied and is discussed in the next section.

Overall, parents of paediatric patients will occasionally find themselves in conflicting roles. On the one hand they are expected to advocate, protect and make decisions regarding the wellbeing of their child, yet their dependence and subordination to the medical professional means that they will sometimes find it difficult to challenge their authority and question their decisions (Young et al. 2002a). Albeit their own preferences and despite their disagreements
with the medical practitioners, in some instances, parents will adapt to the professionals’ perspective and practice, based on the belief that it is in the best interest of their child that they trust the medical advice given to them (Wilhelmsen and Nilsen 2015). Dominant discourses and expectations constituting notions of ‘good’ parenting will inform parents’ responses to their child’s illness. Some of these roles and expectations are governed by gender norms, reinforced through wider discourse and social structures (discussed earlier in this chapter). Ensuring that they are well informed about their child’s condition and equipped to make decisions about their child’s treatment and care, is thought to be indicative of good parenting for example. However, subordination to the medic’s views, in spite of disagreements and the parents’ own preferences, are also thought to be a moral obligation of ‘good’ parenting (Nelson et al. 2012).

In the following section, parents’ approaches and preferences towards treatment decision-making are examined.

### 3.4 Treatment Decision-Making

Similar to literature describing adult patients’ decision-making behaviours (Gafni et al. 1998 and Charles et al. 199), decision-making involving paediatric patients is thought to occur along a continuum; at one end is ‘autonomous decision-making’, where parents, and/or patient, is responsible for making the decision, and at the other end is the ‘paternalistic’ model of decision-making, where physician has full responsibility. A shared model of decision-making, between clinician and family is viewed as the ideal (Lipstein et al. 2012). Parents’ views about decision-making has been categorised by Kilicarslan-Toruner and Akgun-Citak (2013) into three groups; the physician has authority, the parent has authority, and the parent and physician
share opinions and make decision together. Trusting and communication with healthcare professionals, economic factors, resources and expectations of the healthcare team and the illness situation, are factors thought to affect the decision-making preferences and practices of parents. Parents will choose to rely on the healthcare professionals’ opinion and advice, especially when there is a high level of threat to their child (Pyke-Grimm et al. 2006). Recognising their own knowledge deficit in comparison to the doctors’ expertise, some parents prefer their doctor to guide medical decisions involving serious situations (Pyke-Grimm et al. 2006). The same study suggests however that whilst parents agree and recognise that they initially had limited knowledge and experience, having acquired these over time enables and encourages them to take on a more active role in treatment decision-making. Overall, Pyke-Grime and colleagues (2006) found variability in how parents view and negotiate their responsibility, and that of the doctor, in decision-making concerning their child’s medical treatment.

When it comes to treatment decision-making for their child, parents understand it as their role and responsibility to make sure options are explored and open for their child (Allen 2014). In the section prior, it was suggested that taking steps towards ensuring informed decision are made for their child is thought to be an obligation and indication of good parenting; it is suggested that parents will rely on their healthcare professionals’ opinion, as well as their own research, in order to make informed decisions (Allen 2014). It is advised however, that parents will not be constrained by what the primary clinician offers. According to Bluebond-Langner et al. (2007), having made a recommendation about a cancer treatment, or having explained that there are no options available to combat the disease, the physicians cannot expect parents to conform to their views. In instances when the child does not respond to treatment, parents will reportedly search for additional options and seek second opinions (Einarsdottir 2009).
their review of literature on parent decision-making about their child’s medical treatment, Lipstein and colleagues (2012) identify a number of factors which influence parents’ decision-making. Prior healthcare experiences are thought to influence decision-making practices, where prior experiences and growing understandings of their child’s disease may influence their practices and preferences. Furthermore, recommendations made by clinicians involved in the care of their child are thought to be especially important and influential. Depending on the clinical setting, family members, school staff, other parents and patients with disease-specific experience may also influence parents’ decision-making. Finally, it is noted that the child will also influence parents’ decision-making, where the child’s preferences are considered.

According to Lipstein et al. (2012), decision-making in the context of paediatric settings requires tradeoffs between disease effects, treatment effectiveness and side effects. With increasing rates of paediatric chronic illnesses and the development of new treatments, there is need to understand the decision-making process involving paediatrics. This understanding will enable practitioners and policy makers reduce negative decision outcomes such as stress, worry and regret for example. This research is interested in examining the way parents approach and manage decision-making involving a new type of therapy, i.e. Proton Beam Therapy. As noted in the previous chapter, Proton therapy is a new type of treatment and it is not known how users of the treatment perceive the treatment and how they approach decision-making involving this. For instance, it is not known what sources of information, experience and discourse they draw from and model their views of treatment, and what their expectations from treatment outcome may be.
3.5 Parents Managing their Child’s Illness

Chronic illnesses are experienced and managed in varied ways, sometime dependent on the type of condition. The ways parents manage their child’s chronic illness is the focus of this section. First, parents’ responses to uncertainties and the way they manage these are addressed. Following this, the competing sources of information parents rely on and draw from are outlined. Finally, parental knowledge and the provision of skilled care as a response to managing their child’s illness is examined.

3.5.1 Managing and Responding to Uncertainties

In the previous chapter uncertainty as a key feature of chronic illness was discussed, where a myriad of uncertainties pertaining to diagnosis, the course of disease, future outcomes and patient’s worldviews were highlighted. According to Zinn (2008) approaches to managing and responding to uncertainty fall within a continuum of rational, non-rational and in-between strategies. A rational response to managing uncertainty is to weigh the pros and cons of a situation and based on this make a calculated decision, whereas a non-rational strategy relies on faith, hope and belief. The in-between strategies, comprised of trust, intuition and emotion, are the range of everyday approaches that are neither completely rational nor irrational. Whilst these in-between strategies rely on ‘tacit and pre-rational knowledge instead of explicit scientific proof’, they are effective not only when dealing with limited information but can also be useful when dealing with an overload of knowledge and when ‘heightened complexity prevents or distorts rational decision-making’ (Zinn 2008, p446). Examining the experiences of parents of children with Multiple Sclerosis, Hinton and Kirk (2017) identify four distinct strategies that these parents employ to manage their uncertainties; information searching, continuous monitoring, implementing change and optimism. In their study, Hinton and Kirk
Chapter 3: Literature Review, Part Two: Parenting a Sick Child

(2017) found that whilst parents would systematically gather information related to their child’s condition in order to build framework to understand their child’s illness, they would sometimes also place greater reliance on their experiential knowledge and intuition. Additionally, some parents would avoid certain information and social interactions in order to maintain hope for the future.

Cohen (1995) has demonstrated the way uncertainties involved in childhood illnesses, such as cancer, can give rise to parental uncertainties. According to Cohen, “for families living with a child whose condition is both chronic and life threatening, uncertainty is a constant, for even if the disease is under control or in remission, parents know that it can reoccur with little or no warning” (1995, p66). Indeed, parents’ uncertainties regarding the future and fear of the unknown are reported by Khoury and colleagues (2013) in their study on parents’ experiences involving their child’s cancer, and by Hinton and Kirk (2017) in their study involving parents of children with Multiple Sclerosis. Elsewhere, the experiences of parents of children treated for a brain tumour have been documented, and it is suggested that the completion of treatment does not equate the end of these parents’ worries. In fact, post-treatment accounts of these parents are often rampant with uncertainties concerning the fear of cancer recurrence as well as uncertainties about how their child’s futures may unfold (Lindhal Norberg and Steneby 2009). It is suggested that this is because brain tumours are typically treated with a range of therapies, which subject the patient to persisting sequelae (Lindhal Norberg and Steneby 2009, Hutchinson et al. 2008). In the previous chapter, the role of technologies as a source of uncertainty were discussed.

In an effort to reduce their uncertainty, Cohen (1993) suggests that parents strategically manage information. Cohen identifies two competing styles of information management; in the first
style parents limit the information they receive in order to avoid the risk of encountering information which may exacerbate their fears and uncertainties, in the second style parents seek information vigilantly whilst also discounting the negative information they encounter. In Cohen’s own words, “the management of uncertainty involves developing strategies to manipulate the known, the unknown, and the unknowable” (1993, p85).

Many authors have alluded to the link between information and management of uncertainties (see Eaton Russell et al 2016, Kilicarslan-Toruner, and Akgun-Citak 2013, Jackson 2007 for examples). In their study, involving children with brain tumours and their families, Eaton Russell and colleagues (2016) allude to the uncertainties regarding illness, treatment and future, which pertain the lives of patents and their children. According to the authors, these parents and their children reportedly seek to understand and attain reassuring information as much as possible by talking to other parents, healthcare practitioners and utilising online resources. Elsewhere however, avoidance strategies have been reported (Eheman et al. 2009, Jackson et al. 2007). Jackson and colleagues assert that whilst a lack of information can lead to uncertainty and fears, in some instances too much information can be overwhelming and also create additional uncertainties.

In the previous chapter, the following research questions were posed; ‘What uncertainties do parents face in relation to their child’s experience of illness?’ and ‘What uncertainties do parents face in relation to Proton Beam Therapy?’

The following sub-section examines the competing sources of information that parents draw upon in the management on their child’s illness.
3.5.2 Managing Competing Sources of Information

Seeking health-related information is a way for some people to cope with the uncertainties of their illness and to regain a sense of control (Kilicarslan-Toruner, and Akgun-Citak 2013). More so, seeking and managing health information related to one’s condition has become an important aspect of living with a chronic illness, given the emphasis placed on patient responsibility (Seear 2009) and informed choice (Mazanderani et al. 2019). Parenting a child with a chronic illness requires parents to develop knowledge and skills necessary to take responsibility for the management of their child’s condition (Hinton and Kirk 2017, Smith 2012).

Whilst some parents of paediatric patients will avoid any information or seek limited amounts, others desire to have as much information as possible and rely on various sources of information in order to understand and manage their child’s illness. Access to information is thought to enable these parents to reduce the sense of chaos which ensues following their child’s diagnosis, to create and regain control of the situation in spite of the many uncertainties, whilst also enabling them to advocate for their child and participate in treatment decision-making (Kästel et al. 2011, Björk et al. 2005, Clarke and Fletcher 2003, Jones and Neil-Urban 2003).

It is suggested that the information needs of parents of paediatric patients continuously changes, both in terms of content and amount (Ringer et al. 2011 and Clarke and Fletcher 2003). As parents acquire more knowledge and experience related to their child illness their comprehension process, both intellectually and emotionally, becomes easier and their information needs become more complex and detailed (Kilicarslan-Toruner and Akgun-Citak 2013, Björk et al. 2005). Parents rely on information relayed to them by healthcare
professionals, other parents and families, family friends, printed material and the internet (Kilicarslan-Toruner and Akgun-Citak 2013, Kästel et al. 2011 and Björk et al. 2005). The evidence suggests that parents’ views and use of these different sources of information is varied, and they rely on different sources at different stages of their child’s illness trajectory.

**Healthcare Professionals**

Healthcare professionals are reportedly regarded as the primary source of information by some parents (Kilicarslan-Toruner and Akgun-Citak 2013, Gage and Panagakis 2012, Knapp 2011). During the phase of diagnosis for example, some parents prefer to receive information related to the diagnosis, prognosis and treatment options from a trusted healthcare professional (Gage and Panagakis 2012, Bluebond-Langner et al. 2007). In their study involving parents of paediatric cancer patients, Gage and Panagakis (2012) found that in some instances parents preferred to put their trust in their child’s physician and allow them to filter the information they received relevant to their child’s cancer. Elsewhere, Shortman and colleagues (2013) report that in the post-diagnosis period mothers find it extremely beneficial to be able to ask questions from their child’s physician, although managing and assimilating this information can be difficult for some. The availability of information provided by medical staff, especially in written format, is therefore regarded as a valuable source (Shortman et al. 2013). Literature on the experiences of parents of children with brain tumours suggests that the availability of approachable and knowledgeable healthcare professionals, who are able to offer guidance and reassurance throughout the duration of treatment (Soanes et al. 2009) and post-diagnosis (Jackson et al. 2009), are recognised as important support during this time.

When access to the medical professionals’ input becomes restricted and limited parents will rely on alternative sources of information, such as the internet, in order to source their
information needs. In example, during the later phases of their child’s treatment and post-treatment, as the regular interaction with the doctors and medical staff gradually decreases, parents use the internet in order to supplement the information needs they have (Ringer et al. 2011). It has also been reported that in some instances, parents avoid seeking professional medical help for fear of being labelled neurotic or incompetent (Hinton and Kirk 2017). According to Hinton and Kirk (2017), parents face a range of daily uncertainties during their child’s period of remission, which they are unsure how to manage. In their study, parents described feeling uncertain how to identify and respond to changes in their child’s condition, which resulted in them being reluctant to seek help for fear of being labelled an inadequate parent by medical staff.

The Internet

Whilst the use of the internet amongst parents of paediatric patients is wide-spread (Gage and Panagakis 2012, Ringer et al. 2011, Knapp et al. 2010), research depicting their views and use of online sources of information is varied; where reports of parents both trusting and mistrusting online information coexist. According to some studies, parents make use of this medium with caution since they are fearful of encountering certain kinds of information, such as other families’ tragedies (Gage and Panagakis 2012, Soanes et al 2009). According to Gage and Panagakis (2012), this avoidance behaviour is sometimes employed by parents as a way of coping. This is in line with observations made earlier in this chapter regarding ways parents manage information in order to reduce uncertainties. The fear of being overloaded by various and conflicting forms of information, uncertainty about the accuracy of information, and the advice of healthcare professionals can also lead to apprehension towards parents’ use of the Internet (Gage and Panagakis 2012).
Parents who do rely on the internet have suggested that they regard it to be more up-to-date and easier to access (Walsh et al. 2015). Glen (2015) researched the use of online health resources amongst mothers of children with rare diseases and found that these parents gradually improve their ability to find information and assess its relevance as well as its trustworthiness. The use of the internet as a source of information is reportedly employed in order to seek basic medical information such as the definition of medical terminology, to supplement information related to treatment options given to them by their doctors (Gage and Panagakis 2012, Ringer et al. 2011), and to source disease specific information (Kilicarslan-Toruner and Akgun-Citak 2013). The internet is also increasingly employed by parents in order to access emotional support throughout the child’s illness, and to connect with other patients and families for informational support (Coulson and Greenwood 2011, Gage and Panagakis 2012, Schaffer 2007).

Other Patients and Families

Other patients and their families’ knowledge and experiences are regarded as an important source of information and emotional support for some parents (Kilicarslan-Toruner and Akgun-Citak 2013, Coulson and Greenwood 2011, Schaffer et al. 2007). Accessing real-world examples are reportedly more useful to some parents, than the abstract descriptions offered to them by their child’s team of healthcare professionals (Ringer et al. 2011). Other families’ post-treatment experiences of a specific treatment for example, aids parents to be better informed and prepared for the side effects and how to care for their own child at home (Ringer et al. 2011). Additionally, online parent communities can also play a crucial role in treatment decisions (Schaffer et al. 2007)
Schaffer and colleagues (2007) examined the use of internet amongst mothers of children with genetic disorders to interpret, produce and circulate knowledge related to their child’s condition. According to their study, mothers reported that some of the best information related to treatment options came from other parents. The advice of fellow parents was viewed as reliable since it was based on extensive biomedical research, gathered through extensive research and consultation with experts, as well as real-life experiences. For conditions for which different types of treatments are contested and debated, these mothers were found to especially value the insight and advice of fellow parents. For instance, mothers of children with Prader-Willi Syndrome\(^6\) credited an online parent support group for their decision to opt for experimental and alternative therapies. In one example, Schaffer et al (2007) write about a mother, Heather, who reportedly came across a promising treatment for her child whilst attending a national conference. Having consulted with a paediatric geneticist, who did not support this highly experimental practice, Heather then went online and engaged in chatroom conversations with mothers who strongly advocated that her son begins this particular treatment. Convinced by the evidence gathered by these mothers, Heather then returned to the geneticist and argued her case for her son to start treatment immediately. Heather would then return to these chatrooms in order to compare her son’s progress with other children receiving the treatment and to gather further information. This is an important example, since it highlights the competing sources of information which parents rely on in the management of their child’s illness.

\(^6\) Prader-Willi syndrome is a rare genetic condition that causes a wide range of physical symptoms, learning difficulties and behavioural problems (NHS 2018a).
3.5.3 Utilising Parental Knowledge

In the context of their child’s experience of illness, parents combine their parental knowledge with the provision of skilled care, where the latter involves acquisition of technical competencies. Parents acquire knowledge about the complexities of their child’s disease, treatment options and side effects, and develop skills necessary to manage their child’s symptoms and undertake some treatment work. The range of competencies acquired by these parents, has resulted in them being described as ‘experts’, by some scholars (Ringer et al. 2011, Gunderson 2010).

Informed by their experiential knowledge, parents have a special knowledge of their child, and deploy this to keep check on their child’s health and manage their illness (Kelly and Kelly 2013, Smith et al. 2012, Dimond 2013, Dixon-Woods et al. 2001). In the context of their child’s experience of health and illness, this parental intuition and knowledge of the child is sometimes discredited by the medical professional (Young et al. 2002a). Parents’ struggles to be listened to by the medical cohort are documented in the literature (see Wilhelmsen and Nilsen 2015, Lupton 2013, Lundeby and Tossebro 2008, Dixon-Woods et al. 2005, Young et al. 2002a for examples). A prominent theme in accounts of parents of sick children is the feeling that medical professionals ignore their views and discredit their parental intuition and knowledge of the child. In accounts depicting parents’ experiences of their child’s diagnosis of cancer for example, parents often report levels of frustration in persuading the doctor to listen to them and take account of their parental knowledge (Dixon-Woods et al. 2005).

In parallel to utilising their unique knowledge of their child, parents also acquire new knowledge about the complexities of the disease, treatment options and side effects in order to manage their child’s illness; it is suggested that they do so to regain control over the situation.
Parenting a Sick Child (Alderfer and Kazak 2006) and present themselves as competent parents (Scaffer et al. 2007, Kirk et al. 2005). Parents will also acquire some technical competencies in order to manage their child’s symptoms and undertake some treatment work (Kelly and Kelly 2013, Smith et al. 2012, Woodgate et al. 2008, Alderfer and Kazak 2006, Clarke and Fletcher 2003). In their ethnographic study of families during their child’s cancer treatment, Kelly and Kelly (2013) found parents to be in possession of specialised vocabulary and knowledge, a good understanding of complex biomedical information and were able to identify the rationale behind treatment decision-making, whilst also performing tasks related to caring for their child’s central venous access line. It has been suggested that the performance of these tasks and demonstrated competencies, blur the line between expert professional and lay person (Wilhelmsen and Nilsen 2015, Kirk and Glendinning 2002), where parents and carers have been described as experts (McDonald et al. 2016, Ringer et al. 2011, Gunderson 2010, Kirk and Glendinning 2002). Exploring the experiences of parents caring for a technology-dependent child, Kirk and Glendinning (2002) found parents’ expertise to be rooted in their experiential and intuitive knowledge derived from caring for their child, as well training received through programmes.

According to Wilhelmsen and Nilsen (2015) parents can be described as expert parents, just as much as expert patients are described in the literature of chronic illness. In their study, they found parents to be well acquainted with their child’s illness, competent to systematically reason and interpret clinical signs, and able to educate other parents (Wilhelmsen and Nilsen 2015). Elsewhere in the literature, it is suggested that regardless of the level of medical knowledge patients and their families possess and understand, they are experts by virtue of their experience (McDonald et al. 2016, Vicarelli and Bronzini 2009). Based on this view, patients and their families develop a deep understanding of their illness and develop expertise which enables them to manage complex work and live with the condition.
Whilst parents have been described as experts in the literature, the research which it is situated in is rather descriptive. Little research has examined the type of expertise that parents of paediatric patients possess, and how they have come to acquire this expertise. The following research question was posed in the previous chapter; ‘What types of specialist expertise do parents of children treated with PBT possess?’ In light of the above discussions, the following questions are also posed, ‘How do parents acquire their specialist expertise?’ and ‘What do parents use their specialist expertise for?’. Perhaps these parents acquire their expertise to manage some of their uncertainties pertaining to their child’s disease and proton treatment. Additionally, in line with the above discussion, being well informed about their condition and equipped to make decisions about their child’s treatment and care is thought to be indicative of good parenting.

In the next section the impact of childhood illnesses on parents and wider family, especially siblings, is examined.

### 3.6 Impact of Childhood Illnesses on Parents and Family

In the previous chapter, the concept of biographical disruption was discussed. Biographical disruption has been used as a key concept to explore the disruptive influence of illness onset and progression. The large majority of scholarship looking at biographical disruption is informed from the standpoint of the adult patient, although research examining the experiences of children has emerged. Whilst the literature has primarily focused on an individualistic perspective, the shared nature of the illness trajectory and the impact of this on close significant-others have been highlighted (see Bell et al. 2016, Bray et al. 2014, Wilson 2007,
Young et al. 2002 for examples). This section is focused on the impact of a child’s illness on their parents and family.

When a child is ill and receives a diagnosis, the parents’ parental role and identity undergoes change (Shortman et al. 2013, Woodman 2013, Hallström et al. 2002). Parents become carers, protectors, decision makers and advocators for their child (Bluebond-Langner et al. 2007, Bray et al. 2014). Although not ill themselves, it has been suggested that parents experience many of the consequences of chronic illness, such as biographical disruption, compromise in role function and deterioration in quality-of-life for example (Young et al. 2002). Bray and colleagues (2014) examined the interaction between different biographies within a family with a sick child. Based on interviews with children and their parents, they looked at how the biographies of children and their parents can be influenced following surgery and ongoing management of a long-term continence condition. They found that parents’ biographical experiences following their child’s surgery were entwined with the development of their child’s biography, although these experiences were not necessarily aligned. They have grouped their findings into three categories; ‘enriched parental biographies’, ‘continuity in parental biographies’ and ‘disrupted parental biographies’. Following their child’s surgery some parents described a sense of enrichment; the surgery had enabled their child to manage their condition independently and had discharged these parents from their caring role. Parents spoke of their new-found ability to fulfil previously unachievable aims and opportunities. Bray and colleagues describe this as ‘enriched parental biographies’. In some instances, the surgery was described by parents as just another step in their child’s medical history. In these instances, the dependent identities of the young person had become such an integral part of the parents’ biographies, that despite efforts by the young person to develop autonomy and independence, the ‘continuity of their parents’ biographies’ and perceived need to continue to manage their
child’s condition limited these efforts. The ‘disrupted parental biographies’ describes occasions where parents spoke of their feelings of loss and disruption. According to these parents the increased independence of their child, following surgery, had left them feeling unwanted and at a loss as to how to fill-up spare time which was once occupied with illness-related work. Bray et al. (2014) observe that the young person and their parents’ biographies become embedded and entailed with one another.

With a focus on mothers of paediatric cancer patients, Young and colleagues (2002) have suggested that biographical disruption begins when they first notice their child is sick and intensifies when a diagnosis is given. This disruption alters the mother’s sense of self and their identity, and actives the construction of a new identity; this new identity brings new responsibilities and new roles. A child’s diagnosis sets in motion a number of new identities, such as technical and nursing roles, whilst also intensifying a number of existing roles and obligations; namely obligations around protection and responsibility (ibid). A key obligation generated by the diagnosis of childhood cancer is the felt need for mothers to be physically close to their sick child at all times, in order to provide comfort and keep watch; otherwise known as ‘obligation of proximity’ (ibid). However, whilst the obligation of proximity is sometimes found to be a source of comfort to mothers, affirming their effectiveness in the caregiving role, this obligation to be close to the sick child can also lead to a strain on their other roles; namely their parental role towards their other children (Dixon-Woods et al. 2005, Dixon-Woods et al. 2003, Young et al. 2002). It is suggested that the prevailing cultural standards of good parenting which stipulate that parents divide their time, attention and affection equally amongst all their children, is compromised and challenged by the demands and expectations brought about by the diagnosis of paediatric cancer (Van Schoors et al. 2018, Long and Marsland 2011). When a child is diagnosed with cancer, the focus of the family shifts
entirely towards the sick child, where the majority of the parent(s)’ time and attention is steered towards the sick child. Whilst this new-found attention strengthens the bond between parent(s) and sick child, it places a strain on the relationship between parents and the healthy siblings (Van Schoors et al. 2018) According to Van Schoors and colleagues (2018) parents struggle to care for the diagnosed child and at the same time maintain their parental role towards the siblings. Mothers of paediatric cancer patients reportedly experience guilt, conflict and regret for being away from their other children (Young et al. 2002).

The parental role and duty towards the sick child reportedly also compromises and subdues the parents’ other roles and responsibilities; namely their employment role, partner role and friend role (Van Schoors et al. 2018, Lindhal Norberg and Steneby 2009). The diagnosis of a serious childhood condition, such as cancer, generates a crisis which places significant strain on the marital/parents’ relationship, as a result of the uncertainty, stress and anxiety (Van Schoors et al. 2018, Silva-Rodrigues et al. 2016, Da Silva et al. 2010). It has been noted that during the period of treatment, parents reportedly can find it increasingly difficult to combine their parental role with a partner role (Silva-Rodrigues et al. 2016, Swallow et al. 2011). Research by Silva-Rodrigues and colleagues (2016) examined the impact of a child’s cancer diagnosis on the parents’ marital dynamics and found that the demanding nature of the disease and its treatment requires a reorganisation of roles, which can create a strain on the relationship. Women, for instance, are often found to fully give themselves to the mothering role and abandoning or neglecting their role as wife. An anomaly in their study was the mother who opted to stay in full-time employment, whilst the father adopted a full-time carer’s role. The becoming of the father as the child’s reference figure caused the mother to feel guilt, which subsequently interfered in the relationship with her partner.
The diagnosis of a condition can cause profound disruption to the patient, as well as their close family members and associates (Bell et al. 2016, Wilson 2007). The diagnosis of a childhood condition can disrupt the lives of their parents and family. In the case of serious conditions, such as childhood cancer, the diagnosis generates a crisis and challenges the lives of the diagnosed child, their parents and their siblings too (Van Schoors et al. 2018, Kerr et al. 2007, Alderfer & Kazak, 2006, Sloper 2000). The family’s sense and meaning of normality and security reportedly breaks down, and is replaced by fear, uncertainty and chaos (Björk et al. 2005), which can reportedly last long after diagnosis and treatment (Woodgate 2003). The diagnosis can place considerable strain and demands on the family life, although in some instances it is noted to have brought family members closer together (Van Schoors et al. 2018, Khoury et al. 2013).

Having a brother or sister with a chronic condition can affect the lives of siblings. Siblings reportedly experience a profound sense of vulnerability, insecurity, uncertainty and sometimes jealousy, since their parents spend increasingly more time and attention towards their sick sibling (Björk et al. 2005, Dixon-Woods et al. 2005, 2003, and Sloper 2000). Siblings miss the presence of their parents during the acute phase of illness when parents are largely absent due to hospital time (Sloper 2000). Loss of attention and status was reported by siblings involved in Sloper’s (2000) study; as a result of the loss of attention siblings felt like they no longer occupied the same place and importance in the family, as they had done before. However, not all children were found to view the loss of their parents’ attention in negative light, since they reportedly understood why their sibling was receiving more attention than them. Elsewhere, the impact of a sibling’s diagnosis on their brother(s)’ or sister(s)’ social life and leisure activities have been noted (Björk et al 2005, Sloper 2000), with siblings speaking of restrictions to family routines.
Of the impacts of siblings’ illness, children have also revealed that they miss the companionship of their ill brother or sister and spending time with them (Björk et al. 2005, Sloper 2000). Nolbris and colleagues (2007) examined the experiences of children whose brother or sister who was being treated for, or had completed treatment, for cancer. Participants to their study spoke of the possibility of threatening changes to everyday life, where they experienced being anxious about losing their sibling to cancer. Siblings admitted a responsibility to protect and advocate for their sick brother or sister (Nolbris et al. 2007).

3.7 Summary

This chapter has examined literature related to parents’ experiences and responses towards childhood illnesses.

Parental behaviour in response to childhood illnesses is thought to be socially constructed and influenced by wider discourse (Dixon-Woods et al. 2005, McKeever and Miller 2004). Mothers in particular are expected to devote themselves selflessly to the care of their sick child (Lupton 2013, Maher et al. 2009). In the context of children’s experience of health and illness, dominant discourse and expectations pervade notion of what constitutes a ‘good’ mother, where mothers are expected to abide by these codes which stipulate their role and responsibility towards their child (Lupton 2013). Abdicating from these category-bound qualities could lead to mothers being labelled as ‘difficult’ (Lupton and Fenwick 2001). Fathers’ inclusion and response to their child’s illness are also shaped by these wider discourse and social structures, which often exclude fathers (Jones and Neil-Urban 2003, Chesler and Parry 2001). Whilst the role of fathers as providers of care has been highlighted, the majority of research examining
parental experiences of childhood illnesses is predominantly based on mothers’ accounts. In this research every effort will be made to maximise access to fathers’ accounts involving their child’s experience of illness.

It is suggested that analysis of text, such as media accounts for example, can shed light into the cultural component of illness experiences and the constructions of childhood illnesses and expected behaviours by parents, and healthcare services (Dixon-woods et al. 2003, Lupton 1998, 1992). To this end, this research will look at what notion of parents is depicted within information leaflets pertaining to experiences of paediatric proton treatment.

Variability in how parents view and negotiate their responsibility, and that of the doctor, in decision-making concerning their child’s medical treatment has been noted in the literature (Lipstein et al. 2012, Pyke-Grimm et al. 2006). Parents rely on their healthcare professionals’ opinion, as well as their own research, in order to make informed decisions. Taking steps towards ensuring informed decision are made for their child is thought to be an obligation and indication of good parenting. This research is interested in examining the way parents approach and manage decision-making involving a new type of therapy, i.e. Proton Beam Therapy. As noted in the previous chapter, Proton therapy is a new type of treatment and it is not known how users of the treatment perceive the treatment and how they approach decision-making involving this.

In the previous chapter uncertainty as a key feature of chronic illness was discussed. In the context of their child’s illness, parents experience a range of uncertainties. Four distinct strategies that parents employ to manage their uncertainties have been identified; information searching, continuous monitoring, implementing change and optimism (Hinton and Kirk
Parents will rely on their experiential knowledge and intuition, whilst also systematically gathering information related to their child’s condition in order to better understand their child’s illness. The previous chapter flagged questions about the uncertainties that parents may face in relation to their child’s illness and proton treatment. The way parents manage these uncertainties will also be examined.

Finally, the impact of childhood illness on parents, and the wider family were noted. The diagnosis of a condition can cause profound disruption to the patient, as well as their close family members and associates (Bell et al. 2016, Wilson 2007). A child’s ill health disrupts and alters the mother’s sense of self and their identity, and activates the construction of a new identity; this new identity brings new responsibilities and new roles. A child’s diagnosis sets in motion a number of new identities, such as technical and nursing roles, whilst also intensifying a number of existing roles and obligations; namely obligations around protection and responsibility. Whilst the obligation of proximity is sometimes found to be a source of comfort to mothers, affirming their effectiveness in the caregiving role, this obligation to be close to the sick child can also lead to a strain on their other roles; namely their parental role towards their other children (Dixon-Woods et al. 2005, Dixon-Woods et al. 2003, Young et al. 2002). Siblings miss the presence of their parents, and experience feelings of loss of attention and status, during the acute phase of illness when parents are largely absent due to hospital time (Sloper 2000).

In this chapter, and the previous one, literature pertaining to experiences of chronic illness and parents’ experiences of their child’s illness have been examined, and research questions have been formulated. A recap of these questions is detailed below;
Chapter 3: Literature Review, Part Two: Parenting a Sick Child

- How do parents understand and form views of their child’s recovery, following proton treatment for a cancerous or benign tumour?

- How do parents speak of their own recovery, following their child’s experience of proton treatment?

- What uncertainties do parents face in relation to their child’s experience of illness?

- What uncertainties do parents face in relation to Proton Beam Therapy?

- How do parents view and understand Proton Beam Therapy?

- How do parents manage decision-making involving Proton Beam Therapy?

- What types of specialist expertise do parents of children treated with PBT possess?

- How do parents acquire their specialist expertise?

- What do they use their specialist expertise for?

- What notion of parents is portrayed across information leaflets?

- How is Proton Beam Therapy depicted in the information leaflets?

The next chapter outlines the methodological approach used to answer these research questions.
Chapter 4: Methodology

4.1 Introduction

This chapter provides an outline of the overall research design, my methodological perspective and the reality and procedure involved in doing my research in order to answer the research questions, stated in the previous chapter. The chapter begins by providing an outline of the overall research design and strategy. Following this, the research process is divided into two parts; part one, outlined in section 4.3, is focused on the recruitment process, collection and analysis of data yielded from interviews with parents. Next, section 4.4 outlines the process involved in the analysis of documents. Ethical considerations and reflections are then discussed in section 4.5 and, lastly, constraints and limitations of the research are considered in section 4.6.

4.2 Research Design

This section will examine the underpinning approach and rationale employed in this research. The section will begin by discussion of the benefits of a qualitative approach and outlines the justification for this stance. Following on from this, features of this research which render it a sensitive topic are outlined, and the approach adopted for this inquiry are justified. Finally, the two modes of inquiry adopted for data collection are outlined and evaluated; in-depth semi-structured interviews and discourse analysis of documents.
4.2.1 Qualitative Approach

The essence of this study is to explore the subjective experiences and perceptions of its participants. Experiences are complex and multi-faceted, where each person will have a different version of an experience and a different understanding (Silverman 2005). Beliefs, emotions, concerns and expectations can shape and be shaped by experiences (Entwistle et al. 2002). The word ‘experience’ can denote something that may have happened to someone, what they felt about the event, or that person’s evaluation of what happened (ibid). A qualitative mode of inquiry was thought best suited for investigating parents’ experiences, since such an approach is thought to be best equipped for examining experiences (Bryman 2008).

Qualitative research is grounded in an ontological stance which regards people’s knowledge, views, interpretations, interactions, experiences and understandings as sociologically interesting and valuable in explaining the social world they are part of (Mason 2002). Underpinned by an inductive approach, qualitative research seeks to enable theoretical concepts emerge from the data (Bryman 2008). Methods utilised in qualitative inquiry provide a richer and deeper understanding of social phenomena than would be obtained from a purely quantitative approach (Silverman 2014). The use of a qualitative approach is encouraged in health-related inquiry which seeks to investigates health, illness or health services from the perspective of the communities and individuals affected and/or the professionals who provide health services (Green and Thorogood 2009).

This study is grounded within a social constructionist perspective. The premise of a social constructionist ontology is that the worlds in which we live in are not just natural objective
phenomena, but are ordered and shaped through a range of social interactions and practices (Potter 2005). In line with this, talk produced within interviews are not regarded as direct representation of the speakers’ experience, but rather a self-reported retrospective account of their experience, shaped by their intervening experiences and the dynamics of the interview encounter (Dixon-Woods et al. 2003, Entwistle et al. 2002). On this note, Dixon-Woods and colleagues (2003) point out that parents, as research participants, will have conflicting motivations when presenting their accounts; on the one hand, their aim is to provide insight into the private world of childhood cancer and to present a ‘true’ account of the experience. On the other hand, however, parents will also be aiming to protect their own identities and those of their children in face of socially constructed notions of childhood, childhood cancer and parenthood produced within public, professional and media discourse. This must be acknowledged during the reflective process of interviewing and when it comes to analysing the data. Additionally, in line with this stance, within discourse analysis of the documents, texts are not to be evaluated in terms of their truth-value, but rather for what reality is being presented and how such a reality is assembled and presented (Phillips and Hardy 2002).

4.2.2 Researching Sensitive Topics

On the surface, qualitative studies do not appear to pose any direct and/or visible impact to their participants, yet they may have emotional consequences; especially if the research concerns experiences of trauma, ill health or issues that are likely to be classed as private (Green and Thorogood 2009). Lee (1993) classes this type of research as sensitive and describes the nature of this as research in which there are potential implications or consequences for the participants or class of individuals represented by the research. Elsewhere, sensitive research has been classified as research which poses an ‘intrusive threat’ and which induces levels of stress (Ali and Kelly 2012). Whilst the proposed methods utilised
in this research present no physical harm to the research participants, or researcher, and does not involve any direct intervention, the topic itself may present emotional distress and discomfort to the interviewees; to this end, the nature of this study is considered a sensitive topic.

Green and Thorogood (2009) assert that in research which sets out to examine sensitive issues, the researcher’s approach, demeanor and method of data collection must convey respect and reflect the participants’ concerns, rather than the researcher’s perspective. The authors refer to the reflections of sociologist Kathryn Ehrich, in which Ehrich describes her experience of being on the receiving end of an interview and notes the discomfort felt when the interviewer pursued their own research agenda rather than acknowledge her opinions and experiences of chronic illness; “there was no dialogue, only the opportunity to answer questions co-operatively or not” (p73, Green and Thorogood 2009). In the design of this research every effort was made to make use of an approach, which is minimally intrusive and well-suited to the needs of its participants. The choice of semi-structured interviews with the parents was partly informed by the need to be sensitive and based on my awareness that each participant will have a very different story to share. I did not want to hinder their story telling and impose my own perspectives by use of structured and specific questions.

In preparing for this research, a paucity of guidance regarding the actual process involved in collecting data concerning sensitive topics was identified. Whilst researchers do reflect on the measures taken when preparing for the conduction of such research, there is limited discussion of the actual process itself. Of the advice available, Parker and Ulrich (1990) recommend researchers to be attuned to the needs of the interviewee and adopt counselling strategies if need be. Researchers are advised to use their awareness and recognise cues indicating distress
and allow time for the participant to cry or express significant emotion. In the design of this research and in preparation for the interviews I sought advice from fellow researchers who had investigated a sensitive topic, and asked them how to prepare and compose myself during the interviews. More so, I also sought guidance from an experienced researcher in the design of my interview schedule. This exercise proved to be useful, where they advised me on the type of language to use, or avoid, during the interview for example. The decision to ask that parents take part in the interview without the presence of their child was based on the assumption that their presence may yield distress. In the actual process itself however, some of the interviewees chose to include their children in the meeting, and at points even encouraged them to share their thoughts. Further reflections and discussions on how I proceeded with the interviews, given the sensitive nature of the topic, are outlined in the later part of this chapter, section 4.3.3.

4.2.3 Interviews

In order to fulfil the objectives of the research, in-depth semi-structured interviews were identified as a suitable (primary) method of inquiry (see section 4.2.1). Qualitative interviews are regarded as a suitable venue for capturing the ways in which subjects experience, understand and interpret their everyday world, since it provides them with the opportunity to describe in their own words their activities, experiences and opinions (Kvale 2009). A semi-structured style of interview was opted for, since this style of interview permits the researcher to loosely set the agenda in terms of topics covered, whilst allowing the interviewee to respond in a manner that determines the importance and relevance of each topic (Green and Thorogood 2009). This style of interviewing is flexible and adaptable (Mason 2002, Fielding and Thomas 2001), and adopting a flexible tool was important to this study for there are various types of tumours treated with proton therapy, different treatment pathways involved and very diverse family circumstances.
Having conducted an initial examination of relevant literature and formulated an understanding of the current research terrain, a topic-centred approach based on a number of themes informed the course of the interviews (see Appendix iv for the interview guide). The loose topic guide acted as a prompt to encourage the discussion of specific topics across all interviews, whilst not hindering the development of unexpected themes (Mason 2002). Topics covered in the schedule included the run-up to the diagnosis, decision-making regarding treatment, experiences and views of the treatment, experiences of the proton centres as well as post-treatment experiences. Interviewees differed in their child’s type of tumour, access route to treatment, the proton centre they had visited and even time-lapsed since completion of treatment. It was hoped that by introducing similar topics comparisons could be drawn from the underlying concepts identified in their responses.

**Single and Joint Interviews**

The decision was made to include both single and joint interviews. A joint interview usually consists of one interviewer and two interviewees. Joint interviews have the potential to aid recollection of events and create a space where interviewees can reflect and discuss the shared nature of their experiences and the constructions of meanings around them (Sakellariou et al. 2013, Morris 2001). Of the benefits of joint interviews with couples, Bjørnholt and Farstad (2014) argue that this joint endeavor can help solve and overcome some problems embedded within the ethical dimension of research. When interviewing couples together, participants are granted control over the common story that they are sharing and therefore shape their joint narration together. More so, the problem of anonymity and consent among interviewees is reduced, as both are present and talking within a ‘public’ setting. The second advantage of using joint interviews is the richness of the data they can produce. The common reflective space
is thought to provide a rich platform for corroboration and disagreement, and enables the interviewer to witness and observe the couple’s behavior and interaction (ibid). Conducting joint interviews with couples is also thought to maximise and encourage men/fathers’ participation within interview studies (Bjørnholt and Farstad 2014).

Joint interviewing is not without its criticism however, where skepticism is cast based on the presupposition that individual interviews are more ‘intimate’ and enable the researcher to access the true voice of the interviewee. This critique is not baseless where the relational dynamics of the couple are thought to potentially constrain disclosure and may even lead to the interview being dominated by one half of the interviewees (Heaphy and Einarsdottir 2012). This is a hindrance and a single interview with each participant may provide more data and insight for the researcher. Nevertheless, these issues provide a level of richness in terms of the relational dynamics, which may be suited to the object of inquiry/research question (ibid). Joint interviewing was my preferred mode of interviewing for I was keen to incorporate the view of both parents (where present), and to especially encourage the inclusion of fathers in my study. However, the onus of choice was given to the participants and they could choose to take part in either a single or a joint interview. The same interview schedule was used in single and joint interviews. Of the 21 interviews conducted, six of these were joint in nature. Reflections on the usefulness of joint interviews is detailed in section 4.3.3.

4.2.4 Discourse Analysis of Documents

The second method employed in this research was a discourse analysis of documents, produced by the NHS as well as their affiliated proton centers based in North America. The aim of this analysis was to examine the way treatment is portrayed and experiences are depicted by these medical voices, and to then examine them in contrast to the subjective experiences of the parents and carers as narrated in interviews.
Lupton (1992) describes discourse as “a group of ideas or patterned way of thinking which can both be identified in textual and verbal communications and located in wider social structures” (p145). Discourses do not simply reflect or describe a reality, knowledge or experience, but rather play an important role in constructing and shaping them (Potter 2004 and Silverman 2001). Discourses are embodied and enacted in a variety of text; including written text, pictures, spoken words, symbols and artifacts for example (Phillips and Hardy 2002). Texts can be considered as a material manifestation of discourse and a discursive unit of analysis (ibid). Texts position and construct individuals, ideas and versions of the world. However, in isolation texts are not meaningful; it is through their interconnection with other text and the varied discourses from which they draw that they become meaningful (Mogashoa 2014, Phillips and Hardy 2002). Discourse Analysis sets out to explore how texts become meaningful and how they contribute towards the composition of social reality (Phillips and Hardy 2002).

Discourse Analysis is primarily concerned with the analysis of texts and the use of language and their role in constructing the world and involves a focus on the sociocultural and political context in which text and talk occur (Potter 2004 and Lupton & McLean 1998, Lupton 1992). Underpinning this methodology is recognition that a given text is not merely a form of written word, but a form of social practice and a variation of a possible representation or explanation of the subject matter (Grime and Ong 2007, Crowe 2000). Discourse Analysis enables an examination of how texts and the use of language construct reality and guide and reproduce dominant ideologies (Lupton 1992). Discourse Analysis is a theoretical perspective consisting of a broad toolkit (Hjelm 2013, Phillips and Hardy 2002). Whilst different perspectives inform Discourse Analysis, examination of data is not dictated by a certain approach, there is no singular method for analysis and it is therefore very subjective; this has been cited as one of
the weaknesses of Discourse Analysis (Osborne and Neale 2009). It is suggested that the best way to learn the craft of analysis is through practice and example (Nikander 2008, Widdicombe 1993). Working collaboratively with experienced analysts is encouraged, where this practice is also thought to reduce the subjective bias which is inherent to discourse analysis (Hjelm 2013, Nikander 2008).

In preparation for this study, I sought out studies holding research objectives aligned with those of this study and which have employed a Discourse Analysis approach to achieve their research outcomes; namely Grime and Ong (2007) and Dixon-Woods et al. (2003). Grime and Ong (2007), explored the construction of Osteoarthritis in patient information leaflets. Adopting a Discourse Analysis approach in their analysis of the pamphlets, Grime and Ong explain that from a Discourse Analysis perspective written text such as patient information leaflets do not simply describe the reality of a condition, but rather by cherry-picking knowledge and evidence over others the reality of the said condition is constructed in a certain way. It is suggested that the language of patient information leaflets does not simply enable an understanding of the ‘truth’ about health and disease, but helps construct particular understandings of health and disease (ibid). Their study found that the nature of discourse employed, the discourse of Osteoarthritis as a disease or illness for example, impacted on how Osteoarthritis, patients and professionals are seen and understood. Dixon-Woods and colleagues (2003) studied accounts of childhood cancer in newspapers and contrasted these with accounts of childhood cancer given by parents during interviews; they adopted a Discourse Analysis approach towards their analysis of the documents. One of the major findings reported in their study involves the depiction of parents and their responses to their child’s cancer; this was discussed in the previous chapter.
4.3 Research Process: Method One, Interviewing Parents

This section outlines a detailed account of the recruitment process and outcome, the characteristics and demographics of research participants and a reflection on the recruitment strategy. The processes involved in interviewing parents is then discussed, followed by an account of data analysis and interpretations.

4.3.1 Recruitment

Having received a favorable ethical opinion from the University of Surrey’s ethics panel, recruitment commenced in late November 2015. In line with the research time-line, approximately six months was initially allocated to recruitment and data collection for this stage of the study. A visual representation of the recruitment timeline is depicted in Figure 8. Recruitment took place via two routes, where I relied on both online and off-line modes of recruitment, i.e. charitable organisations and an online support group. This study initially set out with the intention to recruit participants via NHS health care professionals, however this did not come to fruition; the reasons for this are detailed in section 4.6 where I reflect on the constraints and limitations of the study.

Charitable Organisations

Patients who do not receive approval for funding via the NHS may access PBT by self-funding, or through charities that provide financial aid and support. I recruited two organisations, charity X and charity Y, based on the assumption that they will garner me wider reach to participants, especially non-NHS funded families.

During the early phases of this PhD, and whilst I was assessing the various means of recruiting
participants, I made contact with charity X. The aim of charity X is to provide assistance and financial aid to paediatric patients seeking PBT. Charity X agreed to aid me in recruitment. However, since the charity is a relatively small organisation, liaising with my point of contact at the charity proved to be difficult, where there were often four-6-week gaps between each point of contact. Recruitment via charity X finally commenced in March 2016. I provided the charity with a recruitment poster (see appendix v), which was circulated via their email bulletin, and distributed at one of their events. The organisation was advised that recruitment would last up to six months and was therefore asked to circulate the material for up to six months, unless notified otherwise.

The second charity, charity Y, was added to my recruitment strategy in January 2016. Charity Y is a charity which specialises in offering support and fund-raising for research into brain tumours. The organisation came to my attention and offered to be part of the research via a participating parent. An amendment was made to the ethics application and approved in January 2016. Charity Y circulated the recruitment poster via their email bulletin and webpage. They were advised that recruitment would last up to six months and was therefore asked to circulate the material for up to six months, unless notified otherwise.

**Online Support Group**

A Facebook support group was identified and used for the purpose of recruitment. This online support group is used as a source of information and support for families, carers and patients (mainly adult patients) who are awaiting approval for PBT, are on treatment or have completed treatment. Members of the group largely consist of both NHS funded and non-NHS funded adult patients and parent(s)/carer(s) of younger patients, although there are some young teenage patients, as well as international members as well. The group is a ‘closed’ group and members are screened prior to being accepted into the group, via the group administrators. The group is
acknowledged by the NHS and is one of the few, if not the only, support groups available for proton patients in the UK. Facebook does not provide data relating to the demographics of a group, and since I am not a group administrator I was unable to poll the members. A scan of the group members however does reveal that the group is predominantly female.

The argument to make use of support groups, online and offline, is supported by the notion that these groups are venues where people are more willing to talk about and discuss emotive issues, which is an important element of the proposed study. A significant benefit to recruitment from these groups is the ability of the researcher to target people who share a strong interest in a particular area or who are experiencing very unique personal circumstances. The use of web-based forums is thought to enhance recruitment and compliments the increasing popularity of social networking and use of online sources of information (Kayrouz et al. 2016).

One of the motivations for opting for this particular support group is due to the fact that there are no other Proton Beam Therapy support groups, online or offline, available for UK based patients. Use of this online support group aided access to a hard-to-reach population. Online support groups are also, generally, geographically independent (Stommel and Koole 2010), and this is reflected in the geographical spread evident in my sample. In the context of health-related research, it is also suggested that online recruitment methods can reduce the burden of pressure on participants. Reflecting on the low number of response rate yielded from their Facebook recruitment method, and comparing this to the comparatively higher number of participants recruited through primary healthcare professionals, Balfe and colleagues (2012), suggest that healthcare professionals may have inadvertently placed pressure upon participants to take part in the research. They suggest that perhaps participants felt pressure to take part in the study for fear of disappointing their healthcare providers for example.
The downside of making use of online forums is that it may lead to the exclusion of certain groups of peoples. Despite the widespread use of the internet, a large population of people do not have access to this medium, and/or computer illiteracy may hinder their uptake (Hine 2015, Boydell et al. 2014). Researchers invoking this mode of recruitment need to be mindful of the audiences they reach, and exclude, and possible implications of this to their sample. Additionally, recruitment from support groups may also garner the attention of specific groups of people. Researchers recruiting via support groups will likely access groups of people whom are more engaged in a topic and hold certain views and agendas (Levin et al. 2011, Duffy 2002). According to Ellard-Gray et al. (2015), one of the problems with accessing and recruiting hard-to-reach samples is that it generally yields an undesired sample homogeneity, since recruitment methods are restricted.

Researchers opting for online recruitment are encouraged to invest some time in becoming familiar with the online community prior to pursuing recruitment (Weslowski 2014). This basic measure will ensure that the researcher is aware of the population representing the support group. Having made my research intentions clear with the Facebook group co-ordinator, I was allowed to join the group and was a member, for close to a year, prior to the start of recruitment. During this period, I was an inactive member of the group; no data was captured, no contact was made with group members and I did not contribute to any on-going discussion in the group. Having had access to the group, I was confident that the group is composed of NHS as well as non-NHS funded patients and that by targeting this group I will have access to a large pool of representatives.

Whilst social media, such as Facebook, enables the researcher to disseminate their recruitment material to a wide audience, motivating users to participate in research can be difficult (Balfe
et al. 2012). Strategies for improving users’ interest include working with site moderators (Mendelson 2007), and establishing trustworthiness and authenticity as researcher (Boydell et al. 2014). Prior to the start of recruitment, I asked for the group coordinator’s permission to post in the group. I also asked that they provide members of the group with a few days’ notice informing them of my intentions and for them to endorse my research. I communicated and posted to the group via a Facebook profile set up for the sole purpose of recruitment. For the purpose of authentication my profile was linked to my university webpage and LinkedIn account, and my university email address was listed. Such measures were intended to create and support a trusting research relationship. For the purpose of transparency, I have provided an account of the Facebook recruitment process below. This detailed account outlines my approach towards recruiting from an online community concerning a sensitive topic.

Facebook Recruitment Activity Time-line

-17th Nov 2015- The group coordinator posted to the group, notifying them of my intention to post my recruitment poster and recruit participants to my study.

The post received an immediate and high response; members ‘commented’ on the post indicating their interest. I commented on each individual post and suggested that our correspondence become private via me sending them the Participant Information Sheet to their private inbox. However, the privacy settings of Facebook caused a setback since it would not allow my message to be sent directly and would re-direct the message to their ‘other’ inbox, which is where Facebook filters unknown messages to. Thus, our line of communication was hindered, where I had to go back to each comment and ask members to check their other inbox. This was time-consuming and problematic, since it involved an exchange of a few comments back and forth in order to explain this, and I was wary that this may deter participants. As a
result of the continuous activity on this post however, the post remained at the top of the page and was not bumped down by other posts.

Interest to take part in the research was also expressed by many members of the group who did not qualify the criteria. This was mainly since the group coordinator’s message was not accompanied by the recruitment poster or any specific information about the study. I messaged everyone individually and thanked them for their interest.

-23rd Nov 2015- Recruitment poster was posted to the group.

Based on my experience with the initial post to the group and the difficulty faced regarding initiating a private line of correspondence, the poster was accompanied by a comment asking that interested members send a direct Facebook message or email to me.

-11th Jan 2016- Recruitment poster was reposted to the group.

Approval was sought from the group coordinator to repost in the group. The post was accompanied by a message stating that the research is reliant on a face-to-face interview and that I would be happy to travel and meet participants. During one of my interviews, I had been informed by the interviewee that some parents i.e. group members had suggested that a lack of time and travel restrictions had prevented them from taking part in the study. I therefore took this opportunity to clarify the nature of the study and to explain that I would travel to meet them, where convenient. The preference that interested participants either message or email me in order to open the line of communication was also reiterated. The downside to this was that the post bumped further down the timeline within a couple of days, since the post remained inactive as a result of no comments.

-23rd Jan 2016- One of the interviewees posted to the group encouraging other families to
take part in the research. This was based on their own initiative and I had not asked them to endorse the research in any way. There was an immediate and high response to this post and many group members signed-up to the study.

-23rd February 2016- Recruitment poster was posted to the group.

Approval was sought from the group coordinator to repost. In an effort to boost recruitment of non-NHS families, the poster was accompanied by a post which explicitly outlined my interest in recruiting and interviewing non-NHS/self-funded families.

**Figure 8: Visual Recruitment Timeline**

**Snowballing**

Snowballing also came into effect and yielded two participants. Many of the interviewees offered to spread word of my research and some of them actively did so via including me in a joint Facebook message or email with another parent, or by forwarding my contact details.
Summary of Recruitment Yield

Overall, the recruitment drive, online and off-line, yielded 38 responses. Of these 38 responses, 21 of them resulted in face-to-face interviews, which comprise the data of this research.

Table 5 depicts the successful recruitment route of the 21 interviews. 17 of the participants were recruited as a result of my post to the Facebook group. One participant joined the research as a result of the endorsement of a participant within the Facebook group (see above, timeline event ‘23rd Jan 2016’).

Two participants were recruited to this study via snowballing method. The charity recruitment method garnered three responses, but only one led to a successful interview.

Table 5: Recruitment Methods and Yield

<table>
<thead>
<tr>
<th>Item Number</th>
<th>Recruitment Method</th>
<th>Yield</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Charitable Organisations</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Researcher’s Facebook Post</td>
<td>17</td>
</tr>
<tr>
<td>3</td>
<td>Snowballing</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>Parent’s Endorsement on Facebook</td>
<td>1</td>
</tr>
</tbody>
</table>

It is evident that recruitment via the Facebook group was most successful; Figure 9 provides a breakdown of the participants accessed via this mode of recruitment, and the number and type of interviews which it resulted in. The yield of item numbers 2 and 4, from the above table, have been combined and consolidated as Facebook yield in the diagram below. Recruitment from Facebook resulted in 18 interviews; six of these were joint interviews and the remaining 12 were single interviews. Of the six joint interviews, one was arranged by the father. Two of the single interviews were with fathers, and 10 singles interviews were carried out with
mothers; of these 10, one of them was initiated by their child 7.

Reflections on Recruitment Strategy

Recruitment via the charitable organisations proved to be challenging at times. Liaising with a third party was time consuming, especially since they could be slow at responding to my contact, and sometimes even failed to respond. Relying on them to distribute the recruitment material was therefore challenging. Whilst I had a good idea of the general audience I would be targeting via the Facebook group, I did not have a clear picture in terms of the charities’ audience. One possible explanation for the poor recruitment yield from the charities could be due to their target audience; charity Y specialises in support for brain tumours, and whilst PBT is largely used to treat brain tumours, it is possible that they only make up a very small portion of the charity’s audience.

Recruitment via the online support group proved to be most successful, for it was aimed at a

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7 *The child was in fact the older sibling of the patient. They contacted me and provided me with a contact email for their mother, asking that I forward the information sheet.
very targeted audience. More so, the mode of recruitment itself, i.e. Facebook also played a major role in this fruitful outcome. Granted the ability to directly post my recruitment material to the group was especially beneficial, for I had control over when to interact with my audience, as opposed to the charitable organisations where I had no control over. Having been a member of the group prior to the start of recruitment, I was familiar with members’ reaction to posts which defied the purpose of the group, e.g. posts which were advertising or requesting sponsorship were frowned upon. I was therefore wary of posting too much to the group and always ensured that the group coordinator was happy that I do so. Keeping a close eye on the group activity also ensured that I did not post my recruitment poster at inappropriate times. For example, when it came to refreshing my round of recruitment, I became aware that a group member had recently lost their child and there was a lot of messages of condolences being posted to the group. I therefore waited and posted to the group approximately 10 days later. I would also aim to post my recruitment material or follow-up posts at weekends or late afternoons, for this was usually when members were most active. The inbuilt messenger tool of Facebook also proved to be invaluable for it enabled real-time correspondence. It allowed for a private and brief venue for correspondence and made scheduling and arranging meetings easier. It is also noteworthy that posts which were sent out by the group coordinator and group member i.e. one of my interviewees, were the most popular and well received posts and yielded most responses. However, these were soon lost to more important and relevant posts in the group. Despite 35 of the users indicating an interest in my study, only 18 of these led to successful recruitment. It is possible that the request for a face-to-face interview may have deterred these people.

Close to 90% of my sample were recruited via the online group. It is important to note that this may have created bias towards parents who may be, or have been, more active in seeking support and information. In analysis of data and reporting on the findings, it is important to be
mindful of the implications of this.

Although this study only managed to recruit a total of 21 participants, this is a relative success considering the total number of paediatric patients travelling abroad for treatment (these numbers are discussed below in detail). Additionally, in comparison to other health related studies which have employed similar recruitment methods, (see Balfe et al. 2012 and Levine et al. 2011), the online method of recruitment employed for this research yielded a good number of participants; both studies employed the use of incentives and contacted group members directly, yet report poor response rates.

**4.3.2 Sample Size, Inclusion Criteria & Participant Characteristics**

**Sample Size**

There are no firmly recognised standards for sample size in qualitative research. Although guiding principles such as data saturation and the nature of the topic are sometimes used when deciding upon a sample size (Baker and Edwards 2012, Mason 2002, Morse 2000). In contrast to the large scale and statistically rigorous sampling in quantitative inquiry, qualitative studies are often based on data derived from small-scale samples. The sample size is kept small in order to allow for the in-depth and intensive analysis that is fundamental to qualitative analysis (Silverman 2014, Bryman 2008). This small sample size however, can lead to scepticisms and concerns regarding the generalisability of research findings and whether findings of the study are representative of all members of the population from which a case has been selected (Bryman 2008). In order to address this concern, the qualitative researcher will commonly use purposive sampling (Marvasti 2004, Silverman 2014). This type of sampling is subjective and based on what the researcher views as necessary and essential to addressing the research
question and formulating the knowledge. The sampling strategy adopted within research may also be partly informed by accessibility and convenience (Marvasti 2004, Mason 2002).

The research initially set out to conduct a minimum of 30 interviews; these were inclusive of both joint and single interviews, where a joint interview involving two parents was counted as one unit. The study set out for a reasonable spread across NHS and non-NHS funded groups. After six months of active recruitment, however, 21 (single and joint) interviews were completed; two of the interviews were with non-NHS candidates and the remaining 19 were NHS funded candidates. The final interview took place at the end of May 2016. By this point a level of data saturation had been met, where common themes were starting to emerge. Furthermore, the last push of the recruitment drive failed to produce anymore participants. Based on the latest figures reported in the literature, 743 paediatric patients have been treated with PBT, by the NHS, since the start of the scheme in 2008; see Table 6. Based on this figure the 19 NHS-funded interviewees represent ~3% of the total population, treated until early 2018.

Table 6: Proton Overseas Programme- Diagnosis and age casemix. (Source: Crellin 2018)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Adult</th>
<th>Teenage and young adult</th>
<th>Paediatric</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chordoma</td>
<td>147</td>
<td>18</td>
<td>15</td>
</tr>
<tr>
<td>Chondrosarcoma</td>
<td>86</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td>Low grade glioma</td>
<td>-</td>
<td>16</td>
<td>138</td>
</tr>
<tr>
<td>Ependymoma</td>
<td>-</td>
<td>11</td>
<td>140</td>
</tr>
<tr>
<td>Craniopharyngioma</td>
<td>-</td>
<td>11</td>
<td>87</td>
</tr>
<tr>
<td>Rhabdomyosarcoma</td>
<td>-</td>
<td>8</td>
<td>176</td>
</tr>
<tr>
<td>Peripheral primitive neuroectodermal tumours</td>
<td>6</td>
<td>8</td>
<td>105</td>
</tr>
</tbody>
</table>
Table 7: Number of Patient who had applications declined for proton treatment overseas since 2009. (Source: Parliament UK 2015)

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Declined</th>
<th>Number of Paediatric Patients</th>
<th>Proportion of Paediatric Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009-2010</td>
<td>24</td>
<td>10</td>
<td>42%</td>
</tr>
<tr>
<td>2010-2011</td>
<td>18</td>
<td>4</td>
<td>22%</td>
</tr>
<tr>
<td>2011-2012</td>
<td>39</td>
<td>15</td>
<td>38%</td>
</tr>
<tr>
<td>2012-2013</td>
<td>20</td>
<td>7</td>
<td>35%</td>
</tr>
<tr>
<td>2013-2014</td>
<td>22</td>
<td>10</td>
<td>45%</td>
</tr>
</tbody>
</table>

Inclusion Criteria

The following inclusion/exclusion criteria were applied to the participants:

- Participants must be parents of a child recipient of PBT, based in the UK.
- The patient (child of the participant(s)) must have completed their treatment, i.e. all interviews took place post-treatment, where no time restrictions were applied.
- The patient (child of the participant(s)) must have been aged between 0-16 years at the time of treatment, i.e. fall within the category of ‘paediatric patient’ at the time of treatment.
treatment.

- If a couple agreed to take part in the study, at least one parent or carer must have travelled with their child to the treating centre.

**Participant Characteristics**

This section outlines the characteristics of the research participants, and their families, in tabulated form. Table 8 details the characteristics of the parents interviewed in this study.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Category</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Female</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>8</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Single</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>4</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>White (British)</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>White (Other)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Asian (Indian/Pakistani/Chinese)</td>
<td>2</td>
</tr>
<tr>
<td>Child’s PBT Funding Route</td>
<td>NHS</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Non-NHS</td>
<td>2</td>
</tr>
</tbody>
</table>

Fathers and ethnic minorities are under-represented within the sample drawn, one reason for this may be due to the recruitment method utilised. Fathers, for instance, may not be as active in seeing information online and participating in support groups. Whilst it was hoped that the joint interviews could compensate for poor access to this group of parents, the fact remains that recruiting fathers to such research is not an easy task. The fact that fathers are underrepresented is no surprise, since family-oriented inquiries are predominantly based on mothers’ accounts. This is likely due to the fact that mothers are the primary care takers of children, are more accessible as research participants and are often regarded as more knowledgeable informants.
about their children’s lives (Swallow et al. 2011, Chesler and Parry 2001). As noted above, the Facebook group, was largely comprised of female users; this may have also contributed towards the larger representation of this group in my sample.

There is a higher number of male patients than there are female patients, in this sample. This may be partly due to the fact that the incidence rate of cancer is higher for boys. In the UK, 54% of children’s cancer cases in the UK are boys, and 46% are girls (Cancer Research UK 2018).

Table 9 outlines further information relevant to the interviewees and their families. The listed names are pseudonyms assigned to the participants and their children. The use of age bands and the omission of information related to the sibling adds an additional layer of anonymity, which is of utmost importance given that this is a sample of participants recruited from a very specific group.
Table 9: Participants and their Families

<table>
<thead>
<tr>
<th>Family</th>
<th>Parent(s)</th>
<th>Child (Patient)</th>
<th>Age of child (at point of PBT)</th>
<th>Sibling Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Michelle</td>
<td>Peter</td>
<td>6-10 years-old</td>
<td>3 siblings</td>
</tr>
<tr>
<td>2</td>
<td>Daniel</td>
<td>Lilly</td>
<td>1-5 years-old</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Louise &amp; Callum</td>
<td>Liam</td>
<td>11-16 years-old</td>
<td>1 sibling</td>
</tr>
<tr>
<td>4</td>
<td>Peggy</td>
<td>Ashley</td>
<td>1-5 years-old</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Claire</td>
<td>Emily</td>
<td>11-16 years-old</td>
<td>1 sibling</td>
</tr>
<tr>
<td>6</td>
<td>Ralph</td>
<td>Lee</td>
<td>11-16 years-old</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Graham &amp; Heather</td>
<td>Charlie</td>
<td>11-16 years-old</td>
<td>3 siblings</td>
</tr>
<tr>
<td>8</td>
<td>Hazel</td>
<td>Nick</td>
<td>6-10 years-old</td>
<td>1 sibling</td>
</tr>
<tr>
<td>9</td>
<td>Agatha</td>
<td>Jacob</td>
<td>6-10 years-old</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Tom &amp; Kim</td>
<td>Chelsea</td>
<td>6-10 years-old</td>
<td>1 sibling</td>
</tr>
<tr>
<td>11</td>
<td>Rochelle</td>
<td>Katie</td>
<td>1-5 years-old</td>
<td>1 sibling</td>
</tr>
<tr>
<td>12</td>
<td>Carly</td>
<td>Shane</td>
<td>11-16 years-old</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>James &amp; Carol</td>
<td>Mim</td>
<td>1-5 years-old</td>
<td>3 siblings</td>
</tr>
<tr>
<td>14</td>
<td>Linda</td>
<td>Curtis</td>
<td>1-5 years-old</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Jennifer</td>
<td>Wilson</td>
<td>11-16 years-old</td>
<td>2 siblings</td>
</tr>
<tr>
<td>16</td>
<td>Katriona &amp; Ross</td>
<td>Grace</td>
<td>6-10 years-old</td>
<td>1 older sibling</td>
</tr>
<tr>
<td>17</td>
<td>Kelly</td>
<td>Zara</td>
<td>6-10 years-old</td>
<td>2 siblings</td>
</tr>
<tr>
<td>18</td>
<td>Natasha</td>
<td>Ryan</td>
<td>1-5 years-old</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Rosalin</td>
<td>Mason</td>
<td>6-10 years-old</td>
<td>1 sibling</td>
</tr>
<tr>
<td>20</td>
<td>Judy</td>
<td>Dean</td>
<td>1-5 years-old</td>
<td>1 sibling</td>
</tr>
<tr>
<td>21</td>
<td>Jonathan &amp; Lisa</td>
<td>Emily</td>
<td>6-10 years-old</td>
<td>2 siblings</td>
</tr>
</tbody>
</table>
**Geographic Data**

The following image, Figure 10, depicts the geographic spread of research participants. The use of online method for recruitment may have resulted in this reasonable geographic spread.

![Geographical Distribution of Participants](image)

Figure 10: Geographical Distribution of Participants; size of the circles represents the sample size in each region

Overall, a relatively homogenous group compose this sample. Participants are primarily female, white, married and fall into the category of NHS funded.

**4.3.3 Data Collection**

Having established the initial line of communication via Facebook messenger or/and email, a
Participant Information Sheet was forwarded onto participants. Participants were asked to read through the Participant Information Sheet and then propose a meeting. The response rate to this varied; some parents would sign up immediately, whereas some failed to respond despite their initial interest. I allowed for approximately seven-10 days to make follow-up contact with the latter group. On follow-up, some parents scheduled an interview, some parents offered to get back to me later once confirming a date with their partner (since they were opting for a joint interview), some parents never replied and in one case it became apparent that the child had become unwell and had many hospital appointments lined up, making it difficult for the parent to set a date. The parent was very apologetic and said that they would get back to me. In this case, I removed all sense of obligation by reminding them that there is no pressure to participate and that they can come back to me whenever they feel is the best time; this parent never got back to me.

Participants were invited to take part in a one-to-one interview, at a time and location convenient to them. Where two adults (carers/parents) had agreed to take part in the study, they were invited to take part in a joint interview. Joint interviews were introduced as the preferred choice of method for couples, however, if they chose, one-to-one individual interviews were also available to them.

The majority of interviews took place at the participant(s)’ homes, in some cases however they opted for a public venue such as a café. The choice of location was always given to the participant, however in one case where I was tasked with suggesting a location, I checked out the venue and ensured that it was a quiet location and also offered privacy to the interviewee. A risk assessment was carried out and a procedure was in place to ensure my safety as a lone-worker.
Qualitative Interviews in Practice

The form of interviewing I followed in my research was face-to-face and based on a loose topic guide I had prepared suited for a semi-structured interview (see appendix ii).

Prior to the start of each interview, I ensured the participant(s) had read a copy of the Participant Information Sheet and that they understood the purpose of the research and their role within it. Having provided them with the opportunity to ask further questions and clarify any issues, I proceeded to obtain informed consent. Templates of the consent forms are available in the appendices (see appendix ii and iii). Interviews were recorded on an audio recording device and I also made notes where necessary.

At the start of each interview I reiterated that the participant has the right to stop the interview at any time and can withdraw from the research at any point without providing any reason. Based on my own judgment if I thought that a participant appeared distressed, I offered to pause or stop the interview, or else change the course of the dialogue. In line with the ethics’ committee policy and regulations, I also circulated relevant and appropriate information regarding support and access to help to the participants.

Whilst safety and respect within research is geared heavily towards participants involved in research, the needs of the researcher, i.e. interviewer must not be overlooked. According to McCosker et al. (2001), research on sensitive topics needs to be carried out in a supportive environment, where physical, emotional and psychological wellbeing of the interviewer and interviewee are considered equally. I therefore ensured that support services were in place for myself and that I had access to the University’s Student Service Centre and counselling services.
Reflections on Single Interviews with Parents

Prior to the start of each interview, I would check with the interviewee whether they have any time constraints and would remind them that they can ask me to stop and leave at any point. Having ensured that they have read and understood the Participant Information Sheet, I would then proceed to obtain their informed consent. I would then start the interview by switching on the audio recorder.

In between signing the consent form and starting the interview, most parents queried my focus on proton therapy and were eager to know what would happen with the results of the study. Having explained the nature of my research and my intention to publicise and share research findings, most parents expressed their motivation to participate in the study as being the desire to help improve the experiences of other patients and their families who will be treated at the UK proton centres, which at the time were due to open in the UK in 2018.

I generally had a very easy rapport with all interviewees and noticed that interviewees were most at ease when the interview took place in their home. The ability to pause the interview and fetch a cup of tea or a photo album of their family and/or from their time at the proton centre, which they were very eager to share, offered the interviewee a short break from the intensity of the interview; an option which was not available to those interviewed in a café for example.

When starting the interview, I would advise the interviewee that my intention is to keep my voice to a minimum and that I invite them to reflect and talk me through any aspect of their experience they would like to share. As a starting point, I would suggest that they provide me with some background to themselves and their family, and to then move on to the point at which they noticed something wrong with their child and sought medical advice. This proved
to be a useful opening, where interviewees would then lead their narrative and talk me through their journey. Where necessary I would ask questions to clarify points or seek a little more detail, but I was wary of not interrupting their dialogue or disrupting the order of their narration. In some instances, the interviewee would pause and ask whether they are talking too much and would instruct me to ask questions, in order to ensure I collect the information I needed from them. In these instances, I would assure them that everything they say is valuable to me and would proceed with a prompt question.

During the interview, I was very aware of my body language and facial expressions. I did not want to come across as ‘feeling sorry’, especially since a number of interviewees had commented on their dislike of being treated differently because of their child’s diagnosis; at the same time however, I did not want to appear too emotionally detached from the interview. If the interviewee became distressed, I would check that they were ok to continue with the interview and would remind them of their right to stop the interview, or change the topic if necessary. Only one of the interviewees appeared distressed during the interview and cried a number of times. I offered to stop the interview at each instance, however the parent was adamant on continuing with her interview, for she was very eager to share her story; this interview lasted up to three hours. The most challenging interview encounter I had, was with a parent who commenced talking about parents losing their children to cancer and the suicidal tendencies of these parents; these comments were made off-record. Whilst I was confident that the interviewee was in no troubled state of mind and was not speaking about themselves, I notified my supervisors of these comments and asked for their advice. Having sent out a thank you email as part of my routine correspondence, I was assured that my interviewee was safe and well.

A challenge which I faced and was unsure of how to best deal with initially, was the presence
of the child i.e. patient and/or their sibling(s) during the interview. In the information sheets, interviewees were asked to be interviewed in the absence of their child, in order to avoid any undue upset. However, in some cases the child and/or their siblings would be present either in the room where the interview was being conducted, or in a room close by. As a researcher and outsider to the family, I did not feel able to ask that the child be removed. In order to address this situation, prior to the commencement of the interview and obtaining consent, I clearly stated to participants that they do not have to talk about matters which make them feel uncomfortable and upset and reminded them that they can ask to pause or stop the interview at any point. In addition to this, I was especially wary of using terms such as ‘cancer’ and ‘tumour’ for example and allowed time to assess how comfortable the interviewee is with using these terms in the presence of their child. In these cases, the parent had no issue with talking about their experience in front of their children; more so, they were very eager for the children to be heard and would re-direct a question at them for example. I did not interview the children and did not direct any interview-style questions at them, and nor did I include any of their comments in my research.

Reflections on Joint Interviews with Parents

Prior to the start of the interview I would ensure that both interviewees have read and understood the Participant Information Sheet. I was wary of the possibility that one half of the couple may have signed up to the study without having read the information sheet. I would then proceed to obtain their informed consent; a separate consent form was created for the joint interviews which provided two tick boxes.

A total of six joint interviews were carried out. In all cases, bar one, the mother had seen the recruitment material and had signed up for the interview. In the case in which the father had
signed up to the study, the couple had separated but were taking part in the joint interview. The
dynamics of this encounter were challenging, where it was difficult to build rapport with the
interviewees and information was not forthcoming. I decided not to prompt for too much
information and cut the interview shorter than I normally would.

During the joint interviews, the mother often dominated the narrative. One reason for this was
that they had often accompanied their child to the proton centre for the whole duration of
treatment, whereas the father had often joined or left them mid-way. Therefore, the mother had
more to say and reflect on about the overall process. In order to encourage the father to speak,
I would direct some questions specifically at them, or would ask for their opinion on the matter
under discussion. However, I was wary of intruding the couple’s dynamics and not interrupting
the speaker.

Joint interviews proved to be useful, where partners would correct one another or validate a
point. If one could not remember something, the other half would step up and fill in the
conversation. More so, the mode of interviewing was also useful where for example they would
check and ask for permission from each other whether to share or talk about a sensitive aspect.
For example, one mother wanted to talk about a sensitive aspect regarding one of her children.
It was clearly very important to the mother and was an aspect which she deemed necessary to
talk about in order to demonstrate the challenges she faced with her other children, as a
consequence of her child’s cancer diagnosis. However, she proceeded to ask for permission
and approval from her husband first and then commenced talking about this sensitive topic.
During this encounter, and prior to the interviewee sharing this sensitive piece of information,
I reminded the couple to only share aspects with which they are comfortable with sharing.
4.3.4 Analysis and Interpretation of Data

All interviews were transcribed by myself, verbatim; I chose to transcribe the ‘umm’ and ‘aah’ of the speaker since this provides some indication of the interviewee’s thought process, and I also did not want to pretend that the parents spoke in a polished, rehearsed, manner. This was a time-consuming task, but very beneficial for it allowed me to become familiar with the data and also improve my interview technique, as I progressed with the other interviews. Transcribing and re-listening to the interviews facilitated an in-depth and intimate knowledge of data. I aimed to transcribe each interview within a day or two of its completion, for I would add side-notes to the transcription based on what took part in the interview; if an interviewee showed me a picture from their phone, scrapbook or photo album for example, I would add a note describing this event to the transcription. More so, if their body language or tone of voice changed notably, I would also add this to my transcript, for it may prove to be useful later during analysis. It was therefore important to do this whilst fresh in my mind. Transcription and analysis of the interviews commenced whilst data collection was ongoing. This reflexive approach enabled me to identify emerging themes and develop them further during subsequent interviews.

Based on my own preference to read hard-copies of material, as opposed to electronic versions, for my initial reading of the data, with the intention of analysis, I used a hard-copy of the transcript. Reading through the transcript in this way facilitated an intimate knowledge of data. Next, interview transcripts were imported into NVivo 10, a computer assisted qualitative data analysis software (CAQDAS). The use of the software aided the process of coding the data into conceptual themes. Coding refers to the continuous process of assigning labels to different segments of data in order to identify themes, patterns relationships and process (Hodkinson 2016). Based on an initial analysis of data, themes and patterns were coded. Codes were
detailed and numerous, but gradually became consolidated into more generalized categories. For example, during the initial phase of analysis I looked for the meanings that participants attached to PBT and the way they spoke about the treatment. These initial codes were later consolidated into ‘biomedical model of PBT’ and ‘biographical model of PBT’; concepts from the literature informed the emergence of these codes. The use of Nvivo 10 was especially useful when it came to consolidating codes, (referred to as nodes in the software), into hierarchies. Additionally, the software also facilitates the quick and easy task of cross-referencing of codes and for checking whose interview was informing a code.

4.4 Research Process: Method Two, Document Analysis

This section is focused on the process involved in the discourse analysis of the documents. The aim of this exercise was to uncover assumptions and to reveal the privileged discourse embedded within the official accounts presented to patients and their families, and to compare this to the experiences portrayed and revealed by the parents in their interviews. The process involved in the selection of documents under review, and the approach adopted towards analysis and interpretation of this data is discussed below.

4.4.1 Sample Selection

Once the research questions and areas of inquiry are outlined, the researcher can proceed with selecting text; the choice of text are aligned with the researcher’s objectives. A great variety of text can be used for analysis, where greater number and variety are thought to facilitate wider understanding of discourse, by not privileging dominant accounts (Osborne and Neale 2009). In order to ensure high quality analysis and methodological rigor, May (2001), details a checklist of criteria (based on Scott 1990) to help the researcher ensure they adopt a coherent
and consistent strategy for document selection; these are, authenticity, credibility, representativeness and meaning. Within this study, the criterion for the documents were; documents that are produced by the NHS and their affiliated proton centres, documents that are aimed at and intended for paediatric users and their families. Having identified and accessed the documents, I made sure to check whether different version of the documents existed. In order to ensure the documents selected for analysis are authentic, I contacted the institutions directly and asked that they send me the documents.

Documents which are accessed by and made available to UK based paediatric families, preparing for treatment and travel to the proton centres abroad, were identified and selected as data. In undertaking this analysis, the NHS affiliated representatives at the proton centres i.e. University of Florida Proton Therapy Institute and ProCure Proton Therapy Centre, and a representative of the NHS Proton Beam Therapy programme were contacted and a request was made for documents fitting the following criteria;

- Leaflets or brochures which are part of the standard package of information made available to prospective NHS and non-NHS funded PBT paediatric patients and families.

The NHS directed me to their webpage, (https://www.england.nhs.uk/commissioning/spec-services/highly-spec-services/pbt/), where I accessed the patient guide [1] listed under the section ‘Patient Information’. Accompanying this document were also documents [2] and [3].

1- Guide for families with children receiving Proton Beam Therapy abroad
The patient guide \textsuperscript{[1]} was selected for analysis, since the research was primarily focused on the patient experience and interested in examining patient information leaflets.

The ProCure Proton Therapy Centre FedEx’ed a package containing documents they would normally send out to a prospective patient. The documents \textsuperscript{[4]}, \textsuperscript{[5]} and \textsuperscript{[6]} are also readily available via their webpage and are accompanied by disease specific documents.


5- Proton Therapy for Patients with Cancer: Talk to your doctor about how proton therapy can help

6- Proton Therapy for Children with Cancer: Talk to your child’s doctor about how proton therapy can help

It is important to point out that the ProCure centre does not provide a specific patient guide for paediatric patients and their families, but offers a two-page leaflet about PBT and childhood cancer. Additionally, there is no readily available document specific for the NHS affiliated patients.

University of Florida Proton Therapy Institute forwarded documents \textsuperscript{[7]} and \textsuperscript{[8]}, via email. These documents are also readily available via their webpage.

7- Pediatric (sic) patient: Proton Therapy Program Information
8- United Kingdom Patients: Medical Support FAQs

Six of these documents were selected for analysis (see Table 10). The selected documents fell into the category of brochures and leaflets that are made available to prospective families preparing for their child’s proton treatment.

Table 10: List of Documents Selected for Analysis

<table>
<thead>
<tr>
<th>Title</th>
<th>Source</th>
<th>Reference Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guide for Families with Children Receiving Proton Beam Therapy Abroad</td>
<td>NHS</td>
<td>1</td>
</tr>
<tr>
<td>Pediatric Patient: Proton Therapy Program Information</td>
<td>UF: University of Florida Proton Therapy Institute</td>
<td>2</td>
</tr>
<tr>
<td>United Kingdom Patients: Medical Support FAQs</td>
<td>UF: University of Florida Proton Therapy Institute</td>
<td>3</td>
</tr>
<tr>
<td>Proton Therapy for Patients with Cancer</td>
<td>ProCure</td>
<td>5</td>
</tr>
<tr>
<td>Proton Therapy for Children with Cancer</td>
<td>ProCure</td>
<td>6</td>
</tr>
</tbody>
</table>

4.4.2 Analysis and Interpretation of Data

With the research questions in mind, in analysing the documents, I aimed to unpack the dominating themes informing the narratives presented, examine the way language and imagery have been used to portray and represent these themes and to identify and reveal gaps and silences. Documents were entered into NVivo 10 software, and both text and images were treated as data.
According to Lupton (1992, 1998), discourse analysis is composed of two levels; textual and contextual. The textual dimension is focused on the structures of discourse, where it is focused on micro elements such as the use of grammar, rhetorical devices such as metaphors and the overt meaning of words. Contextual discourse analysis is focused on the macro structures informing the themes and topics. Here, particular attention is paid to the ideologies and social situations informing the theme (Lupton 1992). For instance, in analysing the documents produced by the proton centres, based in North America, I was conscious of the fact that these documents have been produced within a consumer-driven healthcare model.

Analysis of the documents commenced following the collection of interview data, but prior to their analysis. Thus, in line with the discussion earlier, my analysis of the documents does not fit principles of a grounded theory approach in its strictest form; since I no doubt had a set of preconceived ideas prior to analysis. Being informed by the interview data enriched my analysis however, since I was able to identify gaps and anomalies and also recognise aspects of portrayal.

**Textual Analysis**

Two stages of analysis were applied to the text. Based on an initial reading of the text, I coded general categories which began to emerge. Codes such as ‘proton treatment’, ‘doctor’, ‘patient’, ‘family’ and ‘decision-making’ emerged from this initial analysis. Following the initial analysis, a layer of depth was added to the analysis and coding. For example, ‘certainty/uncertainty’ emerged from this second round of analysis, and then I looked for the relationship between ‘treatment’ and ‘certainty/uncertainty’.
With my research questions at the forefront of analysis, in line with a discourse analysis approach I examined the type of language and perspectives informing these texts (Grime and Ong 2007, Lupton 1992); I was especially focused on two different areas; ‘parents’ and ‘proton therapy’. For example, the term ‘technology’ was used by some documents to describe proton treatment, and it gradually emerged that a biomedical view of the treatment dominated the accounts as opposed to a user/patient perspective.

The documents reviewed came from three different sources. When analysing the texts and identifying the key discourses, I was mindful of connections across the document; interconnections are known as ‘intertextuality’ (Osborne and Neale 2009, Grime and Ong 2007). Grime and Ong’s (2007) analysis involved six patient information leaflets on osteoarthritis, and they identified three different areas of discourse across the documents. In their study they report of the dominance of the disease discourse, and evidence their findings based on the fact that five of the documents focused on aspects which inform this view. In analysis of the discourse involving proton therapy for example, I was mindful of the discourse present, or absent, in each document. Using NVivo software, I was able to cross reference and make checks across the different sources of text.

A broad range of themes informed by the interview data, my familiarity and pre-understanding of the proton experience acquired through reading patient blogs and related information, as well as a review of some of the literature on patient information leaflets, was applied to this stage of the analysis. Additionally, familiarity with the subject matter and my immersion in the interview data also enabled me to identify silences and common gaps in the documents.
Chapter 4: Methodology

The following image, Figure 11, is a screen-shot from my research diary; it outlines the steps involved in my approach and a list of questions I formulated in order to aid analysis.

### Doc Analysis

**Steps of analysis/Qs to ask**

- Study all documents
- Thematic analysis- basic level coding, e.g. ‘family’, ‘patient’, see what emerges
- Second level coding: ‘patient and doc relation’ for example, keep in mind the research questions you have formulated
- Look at similarities and contradictions in the accounts
- If any, what are the differences depicted in the NHS and US accounts? and across the 2 different US accounts?
- Revise documents and think whether it tallies with the accounts you’ve heard from parents?

**Questions/Considerations**

- What do the docs talk and not talk about- what is present/absent? (use pre-understandings informed by interviews to do this)
- What is the focus on in each document? Patient, parent, doctor, technology, cancer, side-effects?
- What evidence is used to back up any scientific claims? Certainty/uncertainty? long term evidence?
- How is PBt presented? Is comparison made to other modes of radiotherapy?
- Any mention of side effects?
- What soft social factors are accounted for?
- How is the parent thought of? Empowered? Knowledgeable? What is their role?
- Any mention of the young person?
- Recovery/post-proct? Where does the story/experience stop in these accounts? How does it begin?
- Positive and optimistic tone? What if anything goes wrong? Are other possibilities considered?

Figure 11: Document Analysis Notes, (Source: Researcher's Research Diary)

**Imagery Analysis**

In analysing visual material, Silverman (2013) recommends asking ‘what is shown’ and ‘how’ questions. Paying attention to stylistic choices is also important for they give meaning to the text and reveal the broader context in which they are produced (Lupton 1992). Two levels of analysis were adopted to the examination of imagery. The first level of analysis relied on an examination of all images as stand-alone images. I cut the images from their parent document and examined them outside of their context. I looked at the content of the images and their size, whilst also paying attention to the way people displayed in the images were presented. NVivo
allowed me to create a memo of these notes and attach it to each image. In the second level of analysis, the images were analysed in relation to their text. For example, I would look to see what caption accompanied the image and the body of text that the image was embedded in.

4.5 Ethical Considerations

Ethical behavior in research requires the researcher to engage with moral issues of right and wrong. To do so, researchers draw on ethical principles outlined in professional guidelines, as well as their own moral outlook. An awareness of the ethical substance inlaid within the research topic and its associated participants needs to be given due consideration at the forefront of research design and conduction. In conducting qualitative research, informed consent, safeguarding confidentiality, respect for privacy, and an awareness of harm to research subjects, as well as researcher, are only some of the matters that need to be considered (Bulmer 2001). However, many issues are emergent and become apparent as the research progresses. In these instances, the researcher will draw on their own moral beliefs to address the issues, whilst adhering to established ethical standards set out for them (Mason 2002). A discussion of anticipated and emergent ethical issues encountered in the design and conduction of this research are outlined below.

This study was reviewed and received a favourable ethical opinion by the University of Surrey’s Ethics Committee in November 2015.

The essence of informed consent means that research participants are aware that they are being researched, are not pressured or manipulated into doing so, they are fully aware of what it means to participate and have the right to withdraw at any time and without any adverse
consequences (Green and Thorogood 2009, Ryen 2004). The right to be informed is commonly address via the use of an information sheet, otherwise known as a Participant Information Sheet (see appendix VI), which details the nature and aims of the research.

In line with this, parents were provided with a designated Participant Information Sheet; The purpose of the study, what their involvement entails, their right to withdraw from the study at any given time, as well as assurance of anonymity were outlined within this document, and reiterated in person. Prior to the interview, I would send the Participant Information Sheet via email, or Facebook messenger, and encourage the participant(s) to read the document before we met; I distributed an additional copy in person, prior to starting the interview. I ensured that all participants read the document and had ample time to ask questions and address any concerns. In the case of joint interviews, I was aware of the possibility that one half of the couple may not have had the chance to read the information sheet prior to the meeting. I therefore handed a copy of the Participant Information Sheet to both interviewees and ensured that they had read this. Following this, I proceeded to obtain informed consent. In cases where the interviewee(s) had brought their child to the interview and the child was on record, I proceeded to check with the parents and the child that they are both ok for me to transcribe their comments; although I did not utilise this data in my study. I transcribed their comments, in order to ensure I did not lose any context surrounding the parents’ talk. In the case of Lee however, I made sure that he read the Participant Information Sheet, and signed a consent form. Lee was close to 18-years-old and was present during my interview with his father. He was eager to take part in the conversation, and was encouraged by his father to do so.

Confidentiality is a key criterion for ethical practice. Confidentiality means not disclosing information gained from an interview in other settings and preserving the identity of the
participant within published accounts (Green and Thorogood 2009). The latter is often addressed by use of pseudonyms and taking calculated measures when describing an individual or organisations. According to Israel and Hay (2006) maintaining participant confidentiality and anonymity in research concerning specific organisations and groups is especially important and equally a challenge. This proved to be the case for this research, since I was recruiting via an online forum and from a relatively small pool of participants. Interviewees would often speak of fellow families they had met on hospital wards and the proton centres, and in some cases when wanting to compare their experience or make a point about a specific issue they would proceed to talk about these other families’ experiences as an example. They would often then ask whether I had met and spoken with these other families. In some cases, it turned out that I had since I could identify these other families based on their names or descriptions given by the interviewee(s); I always refrained from commenting on who I had met. Interview recording and transcripts were kept anonymised and stored in a safe place on campus.

Most ethics committees require the researcher to submit an interview guide to the ethical review board before the investigation may be undertaken, where the board may want/need to approve interview questions in advance (Kvale 2009). This is slightly problematic for research which cannot describe in advance every specific question to be posed and is based on a loose interview guide intended to be flexible and adaptable to each interviewee, i.e. semi structured interviews and narrative interviews. Nevertheless, in line with the mandatory requirements of the committee, I submitted a detailed interview guide listing the possible questions covered in the course of the interviews.

Safeguarding participants is not only limited to matters of confidentiality and anonymity, the topic of discussion and the potential short-term and long-term consequences of the interview
interaction need to be accounted for (Gatrell 2009); this is not only limited to the possible consequences of the final publication, but also involves an awareness of the possibility that the research topic and the interview may lead to changes in self-understanding on the part of the interviewees and/or may cause significant emotional distress (Ali and Kelly 2012). Therefore, in conducting the interviews I ensured that participants were aware of their right to cut the interview short, or stop the interview, if they felt uncomfortable. Based on their body language and response, if I was led to believe that the interviewee felt uncomfortable, I made sure to pause the interview and check that they wanted to continue.

Simple measures were also taken to protect myself as a lone researcher. Prior to each interview I would leave details of my meeting in a sealed envelope with a trusted friend. I would contact this trustee prior to attending my scheduled meeting and advise them to expect a call from me within three-4 hours from the starting time of the interview. If they did not hear from me within this time-frame and were given cause for concern, they were to open the sealed envelope.

4.6 Limitations and Constraints

Several constraints were imposed on the design of this study, the key constraint shaping the study being the one imposed by the ethics committees, which resulted in me having to change the focus of my research. In the initial design of this study I was aiming for a multi-perspective view of the issue under investigation and proposed a study which included the recruitment of NHS based clinicians, paediatric patients and their parents. Constraints imposed by the ethics committees meant that I was only able to recruit parents.
Chapter 4: Methodology

An application was submitted for review by the NHS Research Ethics Committee (REC) so that I could recruit the intended groups of participants via the NHS, as well as the methods discussed earlier in this chapter. An unfavorable opinion was issued by the committee on the basis that, “a great amount of risk [is] attached to the study, in particular studying and questioning children with life limiting conditions as this would cause distress for parents, children and clinicians”. Based on this outcome, the decision was made to eliminate the inclusion of children for I had to consider the time-constraints in place and could not afford the loss of time if my appeal to the panel was to be rejected again. As a researcher, I would argue that the inclusion of children and young people to research concerning them is important and necessary, for they have insights and experiences and are in a position to offer an alternative and rich insight into their experiences. Based on my experience from this study, I would argue that this view is also shared by parents, and even the children themselves. In most cases, parents were eager to have their child present in the interview and would often ask for their opinion on the matter under discussion. Although I did not interview children, children were eager to talk about their experiences, show me their scrap-books, beads of courage and even read to me from their diaries. Whilst I recognise the sensitivity of the issues highlighted by the ethics committee, I would argue that parents and children (depending on their age) should themselves be allowed to decide about participation, based on the information provided to them. Smith (2007) suggests that ethical rigor and guidance can sometimes compromise access to marginalised groups and exclude them from research; this proved to be the case in this instance.

Following the outcome of the IRAS (Integrated Research Application System) application, accounting for time-constraints the decision was made to bypass IRAS and avoid the need for NHS REC approval by excluding paediatric patients, and focusing on recruiting parents via the online forum, and applying for approval from individual NHS premises for the recruitment of
clinicians from their site. An application was submitted for review to the University of Surrey’s Ethics Committee, whilst individual applications were sent out to five different NHS Trusts; these Trusts had been selected based on their specialty and staff profiles, and working with this number of sites was deemed more manageable due to geographical constrains. The outcome from the applications was that I did not require approval since my study fell within the NHS category of ‘Service Evaluation’, rather than ‘Research’, and only involved NHS staff. If I was to interview staff on Trust premises however, I would require a letter of access or an honorary contract. I was therefore advised to arrange for interviews with staff outside of the NHS premises. This process proved problematic however and hindered the recruitment of clinicians. Potential interviewees opted out of an interview after I informed them that the interview had to take place outside of the NHS premises. Scheduling a meeting outside of their working hours and work place also proved difficult. I therefore made the decision to solely focus on the recruitment of parents, and discontinued the recruitment of clinicians.

Recruitment commenced shortly after the high-profile case of Ashya King and my initial round of recruitment was therefore met with a level of scepticism. Following my initial post to the Facebook group, I received a number of emails from clinicians who had been contacted by members of the group who has seen my post and considered it to be a possible journalistic ruse to gather information in relation to the King case. I was asked for proof of my academic credentials by these clinicians and parents. Whilst I aimed to clarify my position in the group and assure members of my intentions, there is no knowing whether this initial scepticism and response to my recruitment drive prevented others from coming forward to take part in the study.
Despite the initial set-backs and challenges I faced in terms of recruitment, I managed to recruit 21 families to this study and collate close to 35-hours of interview data. Proton therapy is a new type of treatment and its use has only recently gained momentum; comparatively speaking, only a small number of patients have received this treatment. This is one of the first sociological studies to examine the experiences of this relatively speaking, hard-to-reach sample.

4.7 Summary

This chapter has provided a detailed outline of the methodological approach and procedure, as well as the method of analysis utilised in the conduction and completion of this research. It has been demonstrated that in line with the objectives of the study, a qualitative approach was best suited. Analysis of 21 interviews and six documents inform the four empirical chapters of this thesis. Data presented in the first chapter is primarily derived from the discourse analysis of the documents, and the final three chapters are informed by the data derived from the interviews. 19 of the interviews fall within the cohort of NHS funded candidates, and two of the interviewees fell into the non-NHS category of candidates. The interviews are comprised of six joint interviews and 15 single interviews. Eight fathers and 19 mothers took part in this study.
Chapter 5: Discourse Analysis of Proton Beam Therapy Information Leaflets

5.1 Introduction

This chapter is based on an exploration and examination of information documents which are accessed by and made available to UK based paediatric families, preparing for treatment and travel to the proton centres abroad. The overarching aim of this exercise has been to reveal the privileged discourse embedded within the official accounts presented to patients and their families. Two research questions inform this analysis; ‘How is Proton Beam Therapy depicted in the information leaflets?’ and ‘What notion of parents is portrayed across information leaflets?’. Asking these questions and juxtaposing their outcome with the accounts presented and discussed by parents in their interviews sheds insight into the different perspectives and experiences, if any, and enables us to look at whether and where these contrasting views are reflected and reproduced and the implications these may have.

Findings discussed in this chapter are based on a Discourse Analysis of documents. Six documents were selected for analysis (see Chapter Four, Table 10, for an outline of these documents). This analysis has helped unpack the dominating themes informing the narratives presented, examined the way language and imagery have been used to portray and represent these themes and has sought to reveal any gaps and silences.

This chapter is comprised of three parts. The opening section, section 5.2, explores the discourse of Proton Beam Therapy (PBT) embedded within the documents and considers the
implications of this for service users’ understandings of the treatment and experiences of illness. Next, the notion of parents and the way they are positioned and situated within the experience of their child’s treatment and interaction within the medical sphere is outlined in section 5.3. Following this, the final section is focused on the gaps and anomalies prevalent in the official discourse; the absence of a post-PBT dialogue, which effectively overlooks the complex notion of recovery, or the missing trajectory of non-NHS funded families are examples of such.

5.2 Discourse of Proton Beam Therapy

The following section examines the way PBT is depicted within official documents that are made available to proton families. Analysis of the documents at hand reveals a discrepancy in the version of PBT presented, where it oscillates between a technology and treatment identity and is embedded within contrasting applications of medical knowledge. Emphasis on the efficacy of treatment and a limited discourse on the side effects and experiences of treatment reveals that a biomedical view as opposed to a subjective/biographical patient view of the treatment carries a greater weight of authority. In fact, given that these are information leaflets about a form of medical treatment, the absence of patient commentary is striking. This section reveals and examines these differences and considers the implications these may have on its service users, i.e. patients and their families.

5.2.1 PBT as a Technology, PBT as a Treatment

Within the University of Florida (UF) brochure [2], proton therapy is first and foremost constructed and presented as a ‘technology’, and then as a ‘treatment’. This technology and
treatment duality is fleshed out in a series of Q&As where the origin of PBT as a piece of technology within physics research laboratories is explained in conjunction to its recent and increased use for the treatment of cancers. A full page of the Q&A series comprises the section titled “Technology”, followed by a shorter three question-long section on “Treatment”, see Figure 12.

Similar to the UF brochure the ProCure patient guide alludes to ‘technology’, sometimes, when describing proton therapy. In the introductory pages of the document, proton therapy is described as an “advanced technology with many advantages”, see Figure 13. Elsewhere, the document states that “Proton therapy is given in proton centres featuring specialized, state-of-the-art medical equipment” (ProCure [4], p4). Use of such language arguably excites the reader and their perspective towards treatment, possibly leading to unrealistic expectations from the treatment.
In contrast to this, the NHS guide\(^1\) never refers to the term ‘technology’ when describing proton therapy; in fact, the term does not appear in the document at all. The NHS document immediately introduces proton therapy as a type of radiation therapy, used to treat diseases such as cancer. “*What is radiotherapy?*”, is the opening question of the Q&A section of the document, which is listed under the section “*Proton Beam Therapy Explained*”. Within this document, the history of the proton therapy is grounded in its radiotherapy roots and the advantages and disadvantages of treatment are outlined.

The following figures are images of the proton beam machinery presented in the NHS\(^1\) and UF\(^2\) documents. The caption accompanying the NHS image of PBT (see Figure 14) refers to it as a ‘treatment machine’; this image is situated under the section entitled ‘*Proton Beam*
**Therapy Explained** (described above). Figure 15 appears on the final page of the NHS brochure, without a caption or description.

The two images of PBT depicted in the UF documents are not accompanied by a caption, but are situated in bodies of text; Figure 16 is wrapped in a body of text entitled ‘technology’ (see Figure 12), and Figure 17 is situated in a body of text entitled ‘Treatment Planning’; the text reads: “your [pediatric] radiation oncologist works with a team of experts in physics and dosimetry to design your child’s treatment plan. Depending on the complexity of treatment, this process may take up to two weeks” (UF [2], p2). Highlighting the different professionals involved in treatment planning, and alluding to the expert physicist and dosimetrist, arguably
adds to the hyped-up technological perspective of PBT that the UF documents embody. The ProCure \cite{4} document follows a similar trend and mentions the various personnel and trained experts involved in proton treatment delivery. The ProCure document does not offer an image of the treatment machinery. However, under a section entitled ‘Proton therapy. What to expect.’ it states the following:

“Proton therapy is given in proton centers (sic) featuring specialized, state-of-the-art medical equipment. The treatment and care is provided by doctors, medical physicists, nurses and radiation therapists who are specially trained experts. The doctor who prescribes proton therapy and manages your medical care is a radiation oncologist” \cite[(ProCure \cite{4}, p5)]{4}

Figure 16: An Image of a PBT Machine, (Source: UF \cite[2], p4)

Figure 17: An Image of a PBT Machine, (Source: UF \cite[2], p2)
An isolated image of the treatment machinery is at the forefront of the visual depiction of PBT, where there are no images of patients undergoing treatment. Beyond the context of their documents the images of these machinery may not be meaningful to the untrained eye. For example, it would not be obvious that these are images of machinery which deliver proton radiation to treat tumours.

Based on the above analysis, the discourse of PBT embedded in these documents can be categorised into two perspectives, the treatment perspective and the technology perspective. The treatment perspective, prevalent within the NHS documents, confirms and instils the notion of PBT as an alternative type of radiation therapy. Albeit the targeted and precise capability of this type of radiotherapy, similar to any other medical procedure and treatment, the risks and uncertainties of treatments prevail. The technology perspective, primarily embedded within the US documents, peels away the therapeutic nature of PBT and focuses on the technology component and capabilities. Under this technology perspective, attention is also drawn to the specialist experts such as physicists and dosimetrists involved in handling of the technology.

**5.2.2 Clinical Certainty and Uncertainty**

In parallel to the technology and treatment dichotomy, a contrasting account of clinical certainty and uncertainty surrounding the efficacy of PBT is evident in the version of accounts.

Erring on the side of caution, the NHS guide\(^1\) offers a cautious depiction of proton therapy, based on the absence of substantial evidence and the fact that radiotherapy is not always successful. Explaining the use of radiotherapy in treating cancerous cells, i.e. tumours, the
Chapter 5: Discourse Analysis of Proton Beam Therapy Information Leaflets

document explains that radiotherapy, “...reduces the risk of the disease coming back and it is successful for many, although not all, patients” (p4). Having established that PBT is in fact a mode of radiotherapy capable of radiating cancer cells in a more targeted fashion, hence reducing radiation dose to surrounding normal and healthy tissues, the document stipulates that “patients may still experience similar side effects and risks of those experienced by other forms of radiotherapy” (NHS [1], p5). Further to this, the document alludes to the lack of long-term evidence available on outcome and efficacy of the treatment;

“Strong evidence of the clinical benefit of Proton Beam Therapy is currently limited and because the service has only been nationally commissioned since 2008 there is relatively little long-term side effect and survival follow-up data.” (NHS [1], p5).

In contrast to this, the UF brochure [2] and the ProCure guide [4] present information about the credibility and clinical benefits of PBT with greater certainty and base these accounts within a well-researched and referenced framework. Uncertainty about the treatment is quashed, where a common question addressed by the two proton centre documents is whether PBT is an experimental form of treatment. Both UF and ProCure state that proton therapy is not experimental and offer the fact that Medicare, Medicaid and the Food and Drug Administration (FDA) have endorsed the treatment, as proof of its credibility. More so, they both refer to the population of 60,000 patients who have been treated worldwide with PBT as proof of its efficacy; although the long-term outcomes of these patients are not addressed. Upon the patient’s request the UF document states that the proton centre will provide access to scientific literature documenting the benefits of PBT for paediatric tumours. The ProCure brochure [4]
and its accompanying guide, ‘Proton Therapy for Children with Cancer’ [6], signpost the reader to a number of journal articles in support of the proven benefits of PBT. A search for these articles revealed them to be under restricted access; where access is granted via subscription to the publishing journal. Overall, the general tenor of the US produced documents is that PBT is a well-researched and established mode of treatment, and the given assumption appears to be a successful outcome from proton treatment, where the possibility of failure and alternative outcomes are unaccounted for.

PBT is therefore embedded within a clinical certainty and uncertainty discourse, which is negotiated and managed differently by the NHS and its US based proton partners. In stating this, it is important to not lose sight of the fact that the UF and ProCure pamphlets are produced within a culture of healthcare largely based on ‘direct to consumer’ advertising, and within each leaflet, the proton centres is in fact trying to sell a healthcare commodity to its reader. In contrast to this, the NHS leaflet is produced in the context of a restricted climate concerning access to PBT; where the rationale underpinning the restricted list of users of said technology is that not all patients will necessary benefit from PBT, and that in some instances conventional radiation therapy can be as equally effective.

5.2.3 PBT vs X-rays, and the Side Effect Discussion

Throughout the documents and at varying levels PBT is juxtaposed with the conventional form of radiation therapy, i.e. X-rays, where the comparative precision and controlled nature of proton therapy and its consequent minimal side effect profile gives it credence. The extracts below are drawn from the NHS booklet [1] and the UF brochure [2];
“Proton Beam Therapy is a type of radiotherapy. It uses protons, which are small parts of atoms, rather than high energy X-rays. This particular type of radiotherapy enables a dose of high energy protons to be targeted directly at the tumour whilst significantly reducing the dose to surrounding tissues and vital organs.” (NHS\textsuperscript{[1]}, p4)

“Proton therapy is a form of radiation which uses protons instead of X-rays...compared to X-rays, it is easier to control protons and this allows more precise delivery of radiation to the tumor [sic]... (compared to conventional radiation therapy) proton therapy has demonstrated an equivalent cure rate with the potential for less acute and long-term side effects.” (UF\textsuperscript{[2]}, p 4-5)

The side effect profile of PBT is presented differently across the documents, where some downplay the effects and others alternate between a long-term and short-term focus. The side effect profile of PBT is significantly downplayed within the UF brochure \textsuperscript{[3]}, where a word search of the document reveals an incident rate of two for the term ‘side effect’; the document alludes to “common radiation side effects” which will be routinely monitored by the clinicians and, as quoted above, explains that in comparison to conventional radiotherapy, PBT has the “potential for less acute and long-term side effects”. Whilst the essence of proton treatment is characterised by a discussion of, reduced side effects, there is no indication as to what these may be and how they will manifest themselves in the patients’ lives; interpretation of the meaning of ‘common side effects’ is purely left to the readers’ discretion. The NHS and ProCure documents pay greater attention to the side effect discussion, with an incident rate of 15 and 12 for the search query on ‘side effect’, in each document respectively. Approximately 50% of the ‘side effect’ occurrences in the ProCure text is in the context of a comparison model to X-rays. ProCure refers to the side effect issue in varied ways and describes proton treatment as having “fewer side
effects”, “reduced side effects”, “minimal side effects”, and wraps it up by suggesting that there may be “no side effects at all”. The ProCure document states:

“As with all radiation therapy, there is the potential for side effects. However, most people report no side effects with proton therapy at all. If they do occur, side effects are generally minor and vary depending on the tumor (sic) location, your general health, other medical conditions, age and medical history. Some people experience tiredness, skin irritation or slight hair loss.” (ProCure, p5)

Within this side effect discussion none of the documents specifically details the nature of the side effects they are talking about; it is left to the readers’ discretion to interpret the meanings of ‘less acute’ or ‘minor’ side effects. The side effect discussion is also mainly focused on the here and now of treatment, where long-term side effects often take a backbench. In fact, the NHS document is the only document which pays due attention to this, where it states, “Side effects can occur during treatment, immediately after treatment or months to years afterwards”, but no specifics are offered as to what these may be.

Furthermore, absent within the context of side effects is a biographical account of patients living and dealing with any PBT related side effects and issues. As will become apparent in the chapters which ensue, patients do in fact contend with a range of side effects during proton treatment and post-treatment. A biomedical model and discussion of side effects, as opposed to a more biographical one, takes precedence within these documents.

This section has shed light on the varied and contrasting portrayals of PBT embedded within the documents. There is tension in how proton therapy is presented and defined, and the way
medical knowledge is applied differently to describe the treatment and its efficacy; some of the implications of this for service users are considered below.

Within the documents, PBT is embedded within a treatment and technology dichotomy. Through the lens of a technology-focused discourse, proton therapy is depicted as a novel cutting-edge mode of technology capable of treating disease with a low-risk of side effect occurrence. In parallel to this, the treatment-perspective presents PBT as an alternative mode of radiation therapy, albeit superior, used to treat cancerous tumours. These contrasting discourses conjure different notions of what proton therapy is, which can manifest themselves in the different expectations and sometimes incorrect understandings of treatment and its outcome on disease. The technology schema, for example, may conjure notions of accuracy, which in turn may result in incorrect understandings and expectations of its efficacy and side effect profile when it comes to decision-making. It will be interesting to see if these different views of PBT are reproduced in the parents’ accounts, and whether this influenced their perception and decision to opt for this treatment for their child. The implications of this are considered in Chapter Six, where it is revealed that parents draw on these different models in order to make or even challenge treatment decisions.

PBT was also found to be embedded within a contrasting account of clinical certainty and uncertainty surrounding its efficacy. It is possible that the contested clinical un/certainty surrounding the treatment may result in false expectations and can potentially fuel false hope surrounding prognosis and the overall experience of illness. In this study, some parents talk about their child’s consultant adopting a more certain and optimistic outlook towards treatment, whilst others talk about their clinicians erring on the side of caution and having doubts about the efficacy of treatment. The way parents manage and negotiate this uncertainty/certainty
dichotomy is especially played out in the case of self-funded families who contest their primary health care’s uncertainty about treatment and opt for the proton centre and alternative medical professionals’ more certain outlook on the clinical efficacy of the treatment. The way these parents negotiate and manage this is expanded in later parts of this thesis.

The PBT vs X-ray and side effects discussion is also paramount to the experiences of proton families and is examined in more detail in Chapter Eight. Being ill-informed about the side effects of treatment can shape the parents’ expectations of treatment in unhelpful ways, and the absence of a biographical and lived dimension to the side effect discussion and experiences of treatment can result in families being unprepared and ill-equipped to deal with them.

5.3 Parents’ Roles and Responsibilities

This section examines the way parents, who are at the forefront of this research, are depicted and assigned roles and responsibilities in the context of their child’s proton experience. The following research question informed analysis; ‘What notion of parents is portrayed across information leaflets?’ To do so, analysis also looked at the way in which other parties to the medical encounter, i.e. paediatric patients and health care professionals, are depicted so to gain sense of the parent identity in relation to these individuals. The section begins by first highlighting the passive role assigned to parents, which markedly overlooks their unique knowledge and experience as well as the medical tasks they are found to perform. Following this, the role of parents as proxy-patient to the clinical encounter is highlighted and discussed, where they oscillate between compliancy and empowerment under the guise of proxy-patient. Within these paradigms the complexity of their roles within their child’s medical encounter, as it emerges in interviews, are largely overlooked.
5.3.1 Passive to the Medical Encounter

The introductory paragraph of the NHS [1] document states the following:

“The doctors looking after your child have recommended that they should be considered for a certain type of Radiotherapy known as Proton Beam Therapy as this is felt to be the best treatment for them... We know that travelling overseas for treatment can be a worrying time for families so this leaflet hopes to answer some of the questions you and your family may have. The leaflet explains how Proton Beam Therapy works, the benefits and the possible side effects. You will also find lots of practical information to help make it easier to organise you and your child’s travel overseas.” (NHS[1], p3)

Within this opening paragraph, the three parties forming the doctor-parent-patient triad are clearly identified and their roles are immediately set out. Within this trio, the doctor’s role is to take care of the child, i.e. patient, and to manage medical aspects of the encounter, i.e. recommend treatment. The patient is identified as ‘your child’, who is being looked after by the doctor, and is thus passively constructed within this clinical encounter. ‘Your child’ affirms the presence of parent(s), whose responsibility is to take charge of organising the logistics and practical aspects of the journey involved in accessing treatment. The term ‘your child’ is used repeatedly throughout the NHS and UF documents, which are targeted specifically at parents, and offer bite-sized chunks of information for the reader. Within these snippets of information nuances of responsibility are assigned to parents, where the most obvious of these tasks is for them to be informed about the steps involved in treatment, to become familiar with the proton centre’s operating system and to ensure they manage logistics and travel arrangements for themselves and their family. The NHS document[1] informs parents of their responsibility to
arrange for visas and accommodation, whilst the UF documents\cite{2, 3} stress the importance of parents taking their child to appointments and ensuring that they are readily available and accessible by the medical team. The role of parent(s) is depicted as coordinator of their child within the medical encounter and is void of any medical knowledge, task or responsibility. The use of imagery within the documents also affirms the distinct roles of parents and medical professionals, and clearly distinguishes the medical workers from the non-medical workers. For example, the only image of a parent and child presented in the NHS\cite{1} document is of a mother with her young daughter, which is outside of a medical context; pictured in a field alongside her mother the child appears physically well (see Figure 18).

![Image of Mother and Child](image.png)

*Figure 18: Image of Mother and Child, (Source: NHS\cite{1}, Front Cover)*

The UF\cite{2} document also presents images of parents and children that are situated outside of a medical setting (see Figure 19 and Figure 20). These images portray a typical nuclear family consisting of mother, father and their two children, a boy and a girl. Both children appear physically well, and it is not clear which of them is the patient. Outside of the context of their document, these images could easily be placed in a family holiday brochure.
In contrast to this, images depicting children alongside clinicians clearly depict the child as a patient and within a medical setting (see Figure 21 and Figure 22). The only image of a medical professional to appear in the NHS document [1] is one which presents a male figure and young girl, both smiling for the camera (see Figure 21). The male figure is clearly marked as a medic since he is dressed in a white coat and his staple stethoscope is draped around his neck. Despite appearing physically well, the young girl is distinguished as the patient, since she is wearing what appear to be pyjamas and is seated in a wheelchair.
Absent within the discourse of parents embedded within these documents is acknowledgment of the medical work that parents carry out for their sick child. Parents are known to play a key role within their child’s experiences of illness (Dixon-Woods et al. 2005, Young et al. 2002). Parents become experts on their child’s symptoms and treatments (Clarke and Fletcher 2003) and, as reported by many parents interviewed for this research, are responsible for carrying out medical work such as changing dressings and feeding tubes, administrating medication and making judgment calls about their child’s state of health prior to, during and post-treatment. Furthermore, as becomes evident in the proceeding chapters, parents take it upon themselves to push for medical tests and check-ups when they disagree with the doctors’ prognosis and
make decisions as to whether they think the doctors’ treatment protocol is appropriate for their child; the latter is particularly evident and demonstrated in the cases involving non-NHS funded families.

5.3.2 Proxy-Patients

In parallel to their distinctive parental role and responsibilities, the position of parents as proxy-patients is stipulated within documents, where they alternate between a compliant patient and an empowered patient engaged in conversation with their health care professionals and actively involved in making decisions concerning their health care and treatment.

The role of the parent(s) as a cooperative parent agreeing to treatment recommended by their child’s doctor is stipulated within the NHS document, with the following quote an example of such;

“Your child’s Clinical Oncologist will refer their case (with your agreement) to
the UK Proton Clinical Reference Panel...” (NHS[1], p6)

Whilst the notion of an agreement implies a level of parent empowerment the terms of agreement appear to be laid out by the medic. The agreement over the treatment pathway is void of any possible challenge and disagreement on behalf of the parent and implies that the parent is agreeing to a recommendation brought about by the doctors. Absent within this documented portrayal are the parent(s) who may challenge or disagree with their doctors’ recommendations. The onus of treatment decision-making is placed on the medical cohort and the role of the parent as an active and informed service user is overlooked. Thus, the parent is
conforming to the traditional notion of a patient who is subservient to the power held by the medical authority. The following extract is from the introductory paragraph in the NHS document. Once again, the onus of medical authority is placed on the doctor(s) who have decided that said treatment is the best treatment;

“The doctors looking after your child have recommended that they should be considered for a certain type of Radiotherapy known as Proton Beam Therapy as this is felt to be the best treatment for them.” (NHS[1], p3)

This scenario outlined in the NHS document does not acknowledge the fact that an alternative pathway to PBT exists. The trajectory outlined in the NHS timeline, (see Figure 23), is for NHS approved cases only and does not recognise a tangent which encapsulates the reality of parents/patients who challenge the panel’s outcome, and who advocate and push for PBT based on their own views of what is felt to be the best treatment.

Figure 23: Timeline of Treatment Approval, (Source: NHS [1], p16)
Chapter 5: Discourse Analysis of Proton Beam Therapy Information Leaflets

The NHS document [1] conveys patient empowerment through the description of parents seeking information, engaging with their child’s doctors and making an informed decision about the recommended treatment. The following example is an excerpt from the NHS document;

“It is extremely important that you discuss the treatment options available to your child with your Clinical Oncologist. This will help you and your child to make an informed decision about whether Proton Beam Therapy is the most suitable option” (NHS[1], p5)

Yet, whilst a degree of patient autonomy is implied and notably relayed to the child patient, and their parent(s), knowledge imparted by the medical professional is what appears to inform and guide this decision about treatment. Any knowledge and expertise brought to the encounter by the parent is unacknowledged. This tension and nuance of contradiction between parent/patient autonomy and compliance is also apparent in the ProCure brochure [4]. In the following extracts, the ProCure document encourages patients to seek information and weight their options before coming to any firm decision about their treatment;

“This brochure will walk you through the benefits of proton therapy and help you make important decisions about your treatment options” (ProCure[4], p1).

“It is important to consider all your options before you decide on a treatment” (ProCure[4], p7)
Here, the onus of decision-making about treatment is relayed to the patient. In an effort to ensure that the parent is adequately informed, the accompanying leaflet, ‘Proton Therapy for Children with Cancer’[^6^], also provides detailed information consisting of references to scientific journal articles and images of MRI scans. The document encourages parents to be prepared when talking about their child’s treatment options and provides a list of questions for parents to prepare and take to their doctor; this of course reflects the consumer lead ethos of the North America healthcare system. The ultimate decision is however delegated to the medical profession, where the brochure states:

> “Only a doctor can help you determine the best treatment approach for you”

*(ProCure[^4^], p4)*

Overall, the documents convey contradictory notions of what is expected from the parents in their role as parents to a sick child and as proxy-patients. On the one hand, parents are constructed within a traditional framework of a doctor-patient model, where the onus of power is largely placed upon the medical party. Yet in parallel to this, the concept of an empowered and informed parent/patient also exists within the documents, where they are encouraged to become informed about treatment and to participate in decision-making. Embedded within this message however is a given assumption that information which informs these views are derived from consultation with the medical professional. In doing so, the knowledge and expertise which the parent(s) bring to the encounter are overlooked. Furthermore, by depicting parents within this framework, the role and experiences of those parents who go against the grain of the medical authority in making decisions about their child’s treatment are overlooked.

This section has highlighted the contradictory notion of parents embedded within the information documents. Parents move between proxy-patient and parent identities, where the
intricacy of each role is overlooked. Parents are largely depicted as passive to the clinical encounter, where their role and responsibility as parents are markedly distinguished from the cohort of medical professionals. Within their role as parents, their expertise and intimate knowledge of their child which partly informs the medical encounter is disregarded. In their role as proxy-patients, parents oscillate between a compliant and empowered patient; where in the latter group, although encouraged to take responsibility and become informed about treatment decision-making, the onus of power is largely assigned to the medical professional. The discourse of parent/patient embedded within the documents reflects prevailing notions of doctor-patient relationships, where the medical viewpoint and authority is privileged and the contribution that the parent/lay person makes is overlooked. As a consequence of this paradigm, experiences of parents who challenge the medical viewpoint and exercise more control over their child’s treatment plan are overlooked, as are the range of work and knowledge that parents conduct and acquire in their experience of their child’s illness. This is in contrast to role, work and knowledge that parents are demonstrated to have, in the previous literature review chapter. Chapter Six highlights the way parents approach decision-making involving treatment, challenge some of their clinician’s views and actively seek out information in relation to their child’s condition and treatment. Additionally, Chapter Seven demonstrates that parents develop a range of expertise, which they deploy and use in the management of their child’s illness and experiences of proton treatment.

5.4 Gaps and Anomalies

The following section examines the overlooked areas of a proton patient and their family’s experiences. Information collated from interviews with the parents enabled the identification of subtle silences and gaps within the documents, which inform this section. The absence of a
post-PBT narrative which accounts for post-treatment experiences was duly noted and is examined in the opening section of this segment, where the implications of this are briefly discussed. The absence of a discourse involving the sick patient and the existence of older paediatric patients is discussed and then followed by a look at family members who play a major role in the reality of the experience, but are overlooked in the documented account. Whilst analysing the documents, an unexpected theme came to light which is briefly discussed in the closing section of this segment, which also looks at the overlooked reality and experiences of non-NHS funded families. In highlighting the unexpected and overlooked, we shed light on the privileged and idealised discourses informing and shaping these experiences.

5.4.1 Post-PBT Narratives

A Proton family’s post-PBT narrative is set out rather sketchily and arguably comes to an abrupt halt in all the documents. The ProCure document talks about ‘Getting Started’, yet it is not clear where and when the proton journey ends. The NHS document provides extensive information about preparing for treatment and the journey abroad, yet offers very limited information for aspects concerning post-treatment. Following suit, the UF Q&A document comes to a sudden halt with the mention of the patient and their family’s return-flight home.

In addition to the missing post-treatment narrative, information provided by the documents about the side effects of proton treatment is also scarce and limited, as demonstrated in Section 5.2.3 of this chapter, and primarily focused on the here-and-now of treatment when mentioned. Efficacy of the treatment is a given and the general tenor of the documents is of PBT being an effective mode of therapy which produces minimum side effects for the patient. This assumption about the treatment and the non-existent post-PBT narrative fails to account for the post-treatment period in which families have to wait for the outcome of scans and test results,
in order to find out whether proton therapy has been successful or not. Parents interviewed for this study referred to this period as a phase of ‘scanxiety’, described as a period of time in which they sit in the dark contemplating the outcome of treatment. More so, the absence of a post-PBT dialogue within the documents means that it fails to acknowledge the fact that the outcome of treatment may sometimes be unsuccessful and/or lead to undesirable outcomes and side effects for the patient. The absence of this post-PBT narrative overlooks the continuity of the patient and their family’s proton trajectory and fails to account for the wider issues at large in the experiences of proton treated patients.

Chapter Eight reveals that the post-treatment period is not always straightforward for parents and their children, and that the notion of recovery is a complex one. When the disease responds to treatment and shows signs of decay, parents explain that this is not the end of their child’s proton journey; uncertainties about the outcome of treatment and the occurrence of undesirable and unexpected treatment related side effects extends the proton trajectory and robs the patient from any meaningful sense of recovery. There are also incidents of relapse and instances where proton therapy fails to produce the desired outcome.

5.4.2 Patient(s)

The focus of this sub-section is on the patients, who are notably absent within the documents. The section opens by examining the striking absence of the sick patient, where by primarily focusing on the biomedical view of treatment and disease effect, the first-hand and subjective experience of the patient has been overlooked. Following this, attention is drawn to the missing older paediatric patients, where the tenor of the documents is steered towards a younger cohort of patients; the existence and views of this group of patients are largely unaddressed.
Ill Patients

Notably absent within the documented discourse of proton therapy is the overall ill-effects of treatment. To begin with, the visual representations of the patients are of smiling patients, (in cases involving both children and adult patients), who appear to be physically fit and well. The text and series of Q&As outlined in the documents also very rarely mentions the ill-effects of the disease and treatment experienced by the patient. Excerpts of the text, which refer to side effects of PBT for example, fail to expand on these or downplay them. Whilst some parents interviewed for the purpose of this research do talk of a smooth treatment pathway with minimum side effects, others speak of an experience in which their child encountered extensive side effects and complications, which left them feeling severely unwell, lethargic and in one instance, traumatised. Additionally, parents refer to a range of on-going health complications which persist post-treatment. The focal point of the documents is on what the treatment is capable of doing at the site of disease and a biomedical model of the disease viewed through the lens of the technology is privileged. As a consequence, first-hand experiences of the patients are not integrated into these accounts, where lay knowledge of patients and their experience of illness are overlooked.

Older Paediatric Patients

For the Paediatric Proton Overseas Scheme, the definition of ‘paediatric’ is taken as up to but not including the 16th birthday at the date of receipt of a complete referral to the panel (NHS 2011). The average age of a child whose parent(s) were interviewed for this study is eight-years-old; the youngest child is two-years-old and the eldest child is 16-years-old. Despite this, the presence of paediatric patients at the older-end of the age scale is largely absent within the documented discourse.
To begin with, all documents are written for a parent audience in mind, where the series of Q&As largely addresses questions about ‘my child’ and ‘your child’. The imagery presented within the documents illustrate a cohort of patients who fall into the younger category of children, (see Figure 18-Figure 22 for examples). Additionally, in describing the daily procedures and delivery of treatment, the descriptions best fit a younger child. For example, the UF brochure states;

“your child will not feel or see the proton beam during the treatment although they may hear unfamiliar sounds such as the rotation gantry. Our child life specialist explains this process in advance during proton preview, a customized age-appropriate pre-treatment visit designed to help prepare your child for radiation. Using pictures, interactive video, therapy mask decoration, and structured play, your child will be better prepared for treatment following a therapeutic and fun session” (UF[2], p3)

Overall, with the documents so heavily focused on the capabilities of proton treatment, we lose sight of the patient. The patients’ views, experiences and needs are largely overlooked.

5.4.3 Family Members

The presence and acknowledgment of the family unit varies notably across the documents.

Whilst the NHS document [1] is a guide for families, it is not clear what is meant by ‘family’. The NHS will fund the cost of travel and accommodation for two parents accompanying the patient but extended family members, including siblings, are not covered. The absence of the family unit is also evident within the imagery, where the father and siblings are notably absent.
Thus, even though the family is mentioned in passing, they are not actively recognised and involved in the experience. This is contrary to accounts given by the interviewees in this study. In all cases, the mothers had travelled with their child to the proton centre and depending on the circumstances, the father had either accompanied them for the full duration, had been present at the start and finish of treatment, or had remained in the UK. Similar patterns were also evident in the presence of siblings in these experiences. Similar to the mothers, many fathers play an important role in their child’s overall medical experience, regardless of having been present for the duration of treatment or not. More so, siblings also play a role and are equally affected by the overall experience and the upheaval of a few or all family members. The absence of fathers within this documented discourse may be attributed to issues previously flagged about the social construction of parenthood and gender expectations, which largely place the onus of care and responsibility on mothers.

In contrast to the NHS account, the UF documents [2,3] depict a family centred philosophy. The imagery included in the document is of numerous and typical nuclear families consisting of mother and father and two children. The variety of patient and family services also provided are aimed at both patient as well as their sibling and parents. The ProCure document [4] also echoes and promotes this family friendly philosophy by inviting patients and their families to take part in luncheons at the centre and share their stories and provide support to one another.

5.4.4 Non-NHS Funded Trajectories

The timeline of events outlined in the NHS document [1] is one which assumes approval from the proton reference panel and a smooth transition to the proton centres abroad. It does not recognise a reality in which the patient/parent may successfully or unsuccessfully appeal the panel’s initial rejection of their case, and nor does it account for instances where the
patients/parents opt to bypass the NHS and, despite the advice of their healthcare professionals’ and the panel’s decision, choose to self-fund for the treatment. The trajectory stipulated within the NHS document is for patients and families complying with the pathway set out for them by their doctors and ignores patients and their families who deviate away from this. This is also evident in an unexpected section in the document entitled ‘Media’, where the document states;

“We understand that you and your family may wish to talk to your local papers about travelling abroad for Proton Beam Therapy, especially if you choose to do fundraising to cover living costs whilst you are away. Whilst we are happy for you to speak to journalists about your child’s treatment, it would be helpful if you could inform our communications team if you are liaising with any journalists so that we can be prepared to provide further comment should we receive a request.”

(NHS[1], p22)

The advice here suggests that families may elect to fundraise in order to cover their living costs abroad. Whilst this is a possibility and some proton families do raise funds in order to cover the costs endured as a result of income loss and the extra costs incurred whilst living abroad, the majority of patients and families who are denied access to PBT by the panel also opt to raise funds so to cover the costs of treatment. It is the latter scenario which often ramps up media attention, with two significant and recent cases as example, (see the Kings[8] and Bevans[9] cases for example). Yet, the document ignores the scenario in which a patient may choose to self-fund their treatment and to speak to the media about this aspect of the fundraising.

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The inclusion of a section on media in the patient information leaflet was at odds with what I have read in information leaflets previously, and I therefore sourced and examined other information leaflets in order to decipher whether the ‘media coverage’ is a common concern for other NHS services. PBT is classified as a ‘highly specialised service’ under the NHS; I therefore decided to source information leaflets for other services which come under this category in order to examine whether the media reference is a concern specific to specialised services. The NHS website lists ‘enzyme replacement therapy’ and ‘liver transplant services’ as highly specialised services, however despite there being a detailed section on PBT, there is no section available for these other two services on their website. I therefore sourced information leaflets for these conditions and services from other NHS webpages. The following two documents, outlined in Table 11, were sourced and a search for media content ensued;

Table 11: List of Additional Documents Selected for ‘Media’ Analysis

<table>
<thead>
<tr>
<th>Title</th>
<th>Source</th>
<th>Reference Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pancreatic enzyme replacement therapy: information for patient</td>
<td>Kings College Hospital</td>
<td>7</td>
</tr>
<tr>
<td>Liver transplantation: What does it mean to me and my family?</td>
<td>Queen Elizabeth Hospital Birmingham</td>
<td>8</td>
</tr>
</tbody>
</table>

The Enzyme replacement document [7] has no mention of media, yet the liver transplantation guide [8] offers a section on publicity and speaking to the media;

“Organ donation and transplantation is often mentioned in the newspapers and on television. Some patients feel so well and happy after their transplant that they
Chapter 5: Discourse Analysis of Proton Beam Therapy Information Leaflets

want to tell the world about it, and they contact the media to have their story told.

If you wish to become involved in something like this we recommend that you contact the transplant coordinators first. They can put you in touch with people who work at the hospital whose job is to work with the media and to provide you with help and advice” (Queen Elizabeth Hospital Birmingham, p7)

Therefore, whilst it is not unique for a section on media advice to appear in a patient information leaflet, the advisory piece in the NHS proton leaflet overlooks an important motivation and aspect of media involvement, which is to raise funds for self-funded patients/families.

5.5 Summary

The aim of this chapter has been to explore information leaflets provided to prospective proton families in order to see how proton therapy and experiences of treatment are depicted. With parents as a focal point of this study, analysis also sought to explore the way they are constructed within these accounts. Two research questions were at the forefront of this analysis; ‘How is Proton Beam Therapy depicted in the information leaflets?’ and ‘What notion of parents is portrayed across information leaflets?’. Discourse Analysis was utilised in order to tease out the privileged discourse and highlight the overlooked entities. Based on information collected during the interviews, this analysis also identified a number of gaps and anomalies.

Focus of the documents is by large on the treatment, where despite the varied and contradictory accounts of PBT given, it takes charge of the trajectory by functioning as a medium through
Chapter 5: Discourse Analysis of Proton Beam Therapy Information Leaflets

which the overall experience is looked at. PBT is depicted as an advance mode of therapy, and uncertainty or scientific conflict in relation to the technology is unacknowledged. The focus is on what the treatment is capable of doing at the site of disease, whilst we lose sight of the patient and their subjective experiences of treatment and illness. The patient and their conceptions of the treatment and disease take a back-bench and we lose sight of the patient and what s/he wants from the outcome of treatment. An implication of this may be that families are sometimes left unprepared to deal with treatment complications and, or even, cope when the desired outcome is not achieved. Imposing this narrow gaze framed around the technology’s capabilities means that the wider complexities of the proton experience and issues relating to post-treatment are overlooked. The overall discourse of PBT becomes the defining feature of the experience, as opposed to the prevailing disease and experiences of illness.

Shifting the focus of analysis onto the parents and their depiction within the documents, it becomes obvious that the intricacy of their role and relation, within the realm of medicine and their child’s experience of treatment, is not fully captured and best fits within an idealized, yet unrealistic, model. Parents oscillate between their parental and proxy-patient roles, where their wider roles are overlooked, and they are expected to meet traditional paradigms of patient-doctor models. This is particularly apparent in the missing narrative concerning non-NHS funded patients and their families. As a consequence of this paradigm, experiences of parents who challenge the medical viewpoint and exercise more control over their child’s treatment plan are overlooked, as are the range of work and knowledge that parents conduct and acquire in their experience of their child’s illness.
The remaining chapters in this thesis draw from the interview data, but comparisons and reflections are made to analysis uncovered in this document analysis. Chapter Six is primarily focused on parents’ views of proton therapy, and their approaches towards decision-making about treatment. Chapter Seven is focused on parental knowledge and expertise, where it is demonstrated that parents develop a range of expertise, which they deploy and use in the management of their child’s illness and experiences of treatment. The eighth and final chapter, ‘Post-treatment Accounts: Uncertain Futures and Recovered Pasts’, is focused on post-treatment experiences with parents talking about long-term medical concerns which prevail in their child’s future and speak of their fears about cancer lurking in the background and the possibly of the disease returning. More so, they talk of the various health issues which have arisen for their child as result of the tumour and treatment related side effects, which have extended their illness trajectory and barred them from any fulfilling sense of recovery; an aspect of the overall experience of treatment which is largely neglected within the discourse examined above.
Chapter 6: Parents’ Understandings of Proton Beam Therapy, and their Practices and Preferences Towards Treatment Decision-Making

6.1 Introduction

This chapter explores the way parents think of and understand proton therapy, whilst also shedding light on their experiences and approaches towards treatment decision-making for their child. This chapter also explores the different pathways involved in these families’ access to proton treatment, i.e. NHS and non-NHS funded routes. Factors which contribute to and play a role in parents’ experiences of decision-making for their child’s treatment are examined. Various factors influence and inform parent’s decision-making and knowledge of treatment; wider discourse, parents’ own research, the input of different clinicians and other families and patients’ experiences inform these parents’ views.

The opening section of this chapter, section 6.2, examines the way parents view and understand proton therapy. Following this, section 6.3. highlights the different treatment pathways involved in these parents’ accounts. In section 6.4, the chapter wraps up by providing insight into parents’ different and varied views about their role within decision-making practices for their child, where notions of good parenting permeates their accounts.
This chapter acts as a stepping stone to the overall thesis, by providing a detailed and descriptive account of the different families involved in this research; their stories have been incorporated and woven into each section.

6.2 Understanding Proton Beam Therapy

The focus of this opening section is on the way parents view and understand proton therapy. The first half of this segment highlights the negative connotations commonly associated with radiation and radiotherapy, which prefigure proton therapy and consequently shaped parents’ initial conceptualisation of proton treatment. In doing so, this research highlights the implications of such framings on users’ perceptions of radiation therapies, and cancer therapies in general. Following this, the next subsection looks at the way parents make sense of this newly introduced treatment, by comparing it to the widely used conventional mode of radiotherapy, i.e. X-ray radiation, also referred to as photon radiotherapy. Similar to the comparison model adopted by the documents, discussed in Chapter Five, parents rely on this comparison in order to formulate their views and make sense of this new type of treatment.

6.2.1 Proton Beam (Radiation) Therapy

A common theme to emerge across several interviews was parents’ mention of their initial reluctance towards PBT, because it is a type of radiation therapy. In the extract below Rochelle recalls her initial response to the doctors’ recommendation of proton therapy as part of her daughter, Katie’s, treatment protocol;

“…initially we (herself and her husband) were quite scared of the word radiotherapy and what it means…”
Similar to Rochelle, Linda was also apprehensive towards radiation therapy and the use of this as part of her son, Curtis’, treatment protocol. Linda explained that Curtis’ young age as well as the targeted area for treatment, i.e. the brain, added to her and her husband’s concerns about the recommended use of radiation therapy;

“...I suppose it was a big blow to us to think that our child who was very young needing any kind of radiation, it was still a very big mental hurdle to get over having our son, you know, having any radiation to his brain and at such a young age...”

The term ‘radiation’ appears to carry negative connotations for both these mothers, although the reasons they hold these views are not made explicitly clear. It is evident however, that their apprehension towards radiation therapy had initially influenced their views of proton treatment. This fear of radiation was also mentioned by Agatha, when asked if she had heard of PBT prior to it being recommended for her son, Jacob. Jacob had been diagnosed and treated for an Ependymoma when he was 14-months-old; his tumour returned however when he turned six. It was during this relapse that proton therapy was recommended in conjunction with a full resection of the tumour. Agatha explained that whilst aware of the treatment she had never contemplated the use of it in treating Jacob’s tumour, because it is a form of radiation. She framed her view of radiation as coloured by what she had learnt from her father, who is a physicist, as well as the information relayed to her by associates who had undergone radiation treatment and experienced unpleasant side effects;

“Interviewer: How had you heard about it, Proton Beam Therapy?

Agatha : I knew that there is such a therapy somewhere, I don’t know where, and it’s good for cancers, and particularly for brain tumours, but, that’s it, that’s all I knew; I didn’t know much about it, because in our mind it was radiotherapy, and
all the horrible side effects and everything would come after radiotherapy, my dad is a nuclear physicist, he works with electrons, not protons, so, but, he, within his job, he was in contact and communicating with people who were working with real radiation, and he’s seen himself the side effects and all that stuff and heard stories and our family friends had side effects and also, it was a pure horror to know that our child has to go through radiotherapy, erm, because even during all these years, I would be refusing any extra CT scan or any extra X-ray, for the sake of not having any extra radiation, it’s just, within our family it’s a little bit, you know, like too much, and we are too sensitive, especially me, because of my dad, erm, so, any sort of radio, contact with radiotherapy and radioactivity seemed to me like a pure pure nightmare, a disaster.”

The extracts above have illustrated that despite PBT being portrayed as an advanced mode of therapy, the fact that it is a type of radiation remains of core importance, and concern, to these parents. Negative connotations associated with radiation therapy prefigured these parents’ view of proton treatment, where they expressed reservations towards the prescribed treatment. These findings confirm the notion that wider discourse and socio-cultural contexts shape expectations of use, and efficacy, of a treatment. Research suggests that uncertainties and misconceptions surrounding radiotherapy, heighten anxieties and influence patient decision-making (ASTRA 2017, Halkett et al. 2012, 2005 and Owens et al. 2003). These parents are drawing from their knowledge and prior experiences involving radiation therapy in order to formulate their initial views of proton therapy, without taking stock of proton treatment’s capabilities and the rationale informing the recommendation to have it.

Despite these parents’ initial concerns, there is consensus amongst them and other interviewees, bar one couple, that proton therapy was the best type of treatment their child
could have had. These parents explain that after learning about PBT’s ability to reduce consequent side effects, compared to conventional X-ray radiation, their initial concerns about proton treatment subsided. The following section highlights the comparison drawn between proton treatment and X-ray therapy by these parents in order to make sense of and justify the use of proton therapy for their child.

6.2.2 Proton Beam Therapy as a Better Type of Radiation Therapy; PBT vs X-ray Radiation

Juxtaposing proton therapy with X-ray radiation therapy was a common approach adopted by parents when talking about their understanding and views of treatment. Parents focused on the differences between the two modes of therapy in order to explain why PBT is the better type of treatment for their child; where the targeted nature of proton treatment and consequent reduced side effect profile were regularly used as way of explaining the benefits of treatment; the outcome of treatment was very rarely mentioned. Some parents distinguished PBT as a superior mode of treatment and explained that it is a better mode of therapy when compared to ‘normal radiotherapy’ or ‘normal cancer treatment’. This comparison model utilised by parents is similar to the discourse adopted throughout the information documents (see Chapter Five), where proton treatment is compared to X-ray radiation at varying levels in order to depict proton therapy in a favourable light, and the focus is largely on the side effect profile of treatment.

In the following extract Rochelle, who at the start of her interview expressed initial hesitations towards radiation treatment (see section 6.2.1), is talking about her understanding of proton treatment and explaining why it is better suited for children;
“...so I know that basically, erm, conventional X-rays, you, you know, an X-ray sort of goes into, the beam goes into the body, but it, instead of it, it comes out in all kind of directions, so it can hit healthy tissues, whereas the proton, erm, basically is a beam that goes in and it can be controlled, it comes out, it comes out without hitting so much of the healthy tissues, erm, so, it’s very important for children to have that because they’re still growing, if you’re having it in a dodgy place of your body, it can have a bad long-term impact, it helps to minimise that damage...”

Proton therapy was recommended by Katie’s doctors immediately after her diagnosis was confirmed. According to Rochelle PBT was pitched as the preferred mode of treatment, by the doctors, due to the location of Katie’s tumour, which was situated on her Submandibular gland. It was explained that proton therapy would minimise damage to Katie’s brain, hearing and other closely located glands. However, despite listing a range of concerns, such as facial disfigurement, hearing, thyroid, fertility, growth and puberty issues which have arisen post-treatment, and loom in the future, Rochelle is adamant that proton therapy was the best treatment available for Katie. Rochelle’s approach towards treatment decision-making is explored in the later part of this chapter, where she regards the doctors’ expertise as best suited to guide such decisions.

Comparison of the beam patterns of both treatments was also adopted by Peggy in order to explain to me why proton radiation is better than standard radiation;

“...the side effect profile is less intense than standard radiation because it (PBT) purely goes through the length, breadth and depth of the tumour, as opposed to standard radiation that goes in and out and buggers everything real fast...”
Although the reduced side effect profile of treatment is at the forefront of her discussion, Peggy later alludes to the lack long-term evidence about this feature and benefit of proton treatment;

“...because it was a new treatment, you didn’t have those longitudinal studies apart from the fact that the side effects are less, you didn’t have what percentage was less, you know...”

As these statements have demonstrated, proton therapy is often compared with X-ray radiation therapy in order to explain how and why it is the better mode of treatment; the side effect profile is at the forefront of this discussion, albeit the lack of long-term evidence and uncertainties. The reduced risk of long-term side effects is the main reason for which this treatment is chosen and/or recommended by the doctors and parents; where the outcome and effects of treatment on the tumour are rarely mentioned when parents talk about PBT. Agatha, who as demonstrated above (see section 6.2.1), was reluctant and fearful towards radiotherapy, here explains that she came round to the idea based on PBT’s ability to minimize long-term side effects;

“...there was a mixture of emotions, but at the same time we were so grateful that there is a possibility of having proton treatment, you know, and erm, what they said, because the tumour is at the back of his head, so it shouldn’t really affect him that much, his IQ, his hormones, because it has, it (PBT) should bypass his hypothalamus and his pituitary gland and all the main structures, apart from his ears,....”

Whilst parents had negative conceptions of PBT due to it being a type of radiation therapy, these negative associations subsided when PBT is juxtaposed with conventional radiotherapy and its features and abilities are distinguished. The ability of PBT to treat tumours in a more
targeted fashion and consequently limit the chances of side effects developing adds to the allure of this treatment. Despite the majority of families alluding to the lack of long-term evidence available on PBT, they view proton therapy in a favourable light; the family at odds with the majority of views speaks about the unexpected side effects that their son has exhibited since completing treatment. Whilst it is not apparent from where these parents derive their knowledge about PBT, it is notable that they are reproducing the comparative model adopted in the information leaflets, analysed in Chapter Five. The various sources of information which parents rely on in order to formulate their views of treatment are explored in the proceeding sections.

The next section explores the different pathways into treatment, recounted by the parents. Whilst highlighting the different experiences of these families, the various sources of information and expertise which inform the decisions to have PBT are considered.

6.3 Proton Beam Therapy; Treatment Pathways

Across the sample of interviewees, parents either fell into the category of ‘NHS-funded family’, or ‘non-NHS funded family’. The latter group categorises the group of parents who opted for their child to be treated with PBT, against the advice of their primary team of doctors and/or the decision panel’s approval; the opening segment of this section is focused on their accounts. Following on from this, the experiences of parents whose child’s proton treatment was recommended, approved and funded by the NHS are examined.
6.3.1 Self-Funded Families’ Accounts

Only two self-funded families were successfully recruited to this study. Whilst it would have been ideal to recruit additional families, having this small number of participants enabled a detailed exploration of their accounts to be incorporated into the body of this thesis.

Hazel is a strong advocate of proton therapy and repeatedly states that PBT is the best treatment available to treat Medulloblastomas. Her son, Nick, was diagnosed with a Medulloblastoma; this type of tumour is not on the NHS’ approved list for PBT. Whilst Nick was recovering from emergency surgery the follow-up treatment plan, i.e. photon radiotherapy, chemotherapy and a further surgery, were laid out to Hazel and her ex-husband by the doctors. Describing a feeling of helplessness in light of this information, Hazel explains that they sought second opinions and did their own research in order to be better equipped at making this “life impacting, life changing and lifesaving” decision; it is apparent that Hazel thinks she ought to have a say in such decisions and not leave it to the doctors alone. Proton therapy, as an option for Nick, came to their attention via two separate ways; it was flagged as an alternative to photon radiotherapy by the various professionals they had contacted, and also via media outlets. Hazel mentions the national media coverage of the Ashya King case (also diagnosed with a Medulloblastoma), as well as their local community’s social media outlets which were raising funds for a neighboring child’s proton treatment.

The primary treating hospital in the UK rejected Hazel’s suggestion for PBT, on the basis that under the circumstances it would not yield an outcome much different to standard radiation treatment. Hazel protests that whilst this view might be correct, “it makes some difference”. The doctors also rejected the option of proton therapy due to the lack of long-term evidence.
Whilst not disputing this fact, Hazel explains that having read about the case of Ashya King she began to wonder “why are they making such a fuss around proton”. However, she remained unsure as to how to proceed given that one of the centres they had contacted was in favour of photon treatment, not PBT, and she was also concerned about the need to travel and leave the UK for several months; the financial cost of the treatment and travel element were an issue. Despite initially agreeing on photon therapy and having Nick prepared for treatment in the UK, Hazel explains that she became very unsure about her decision. She made the decision to opt for proton treatment, a week before Nick was due to start photon therapy in the UK;

“...so Friday, I stood here by this window and decided photon feels all wrong, it was literally, at the end of the day it was a gut decision, if felt wrong, it didn’t feel right...’

Whilst stating that the decision was a ‘gut’ decision, Hazel proceeds with explaining the factors which influenced her decision.

“...I remember sitting here and thinking, it’s wrong, it’s wrong, it’s wrong, this is completely wrong and I went through all the, you know, the lists that we’d made photon VS proton, again I spoke to few more people, I spoke to the boy that they had fund raised for that was already in America and he said, you know, it’s amazing here, people are great and, erm, there’s so many kids that are here being treated on the NHS mostly for various cancers, erm, so I’d spoken to a few more people, I read again through the research, it’s not very much, but there’s a little bit of research on side effects and then I thought, it’s completely illogical to, to expose Nick to photon radiation if he could have proton...”
Chapter 6: Parents’ Understandings of Proton Beam Therapy, and their Practices and Preferences Towards Treatment Decision-Making

The decision to opt for proton treatment came down to the available evidence on PBT’s ability to reduce the side effects of treatment. According to Hazel, the high-risk protocol involving X-ray radiation can be extremely debilitating and will leave young brain tumour patients with severe disabilities due to the high dose of radiation exposed to the brain. The ability of PBT to reduce the occurrence of these side effects is what drove her to opt for this treatment. For this parent, the side effect profile of PBT precedes its efficacy to treat the tumour;

“...there was no evidence that proton is better than photon in treating the cancer
and that is still the case, it’s not better in treating cancer, but it is the better in the
side effects...”

Whilst Hazel mentions that PBT will not treat the cancer any differently to standard treatment and is aware of the limited long-term evidence available in support of PBT, she is comfortable with the decision she has made. She mentions the doctors’ protests about the lack of long-term evidence and her own awareness of the limited research available, but nevertheless is confident in the research she has read and firm in her view that PBT is better suited for her son. In addition to her own research and analysis, Hazel states that having met with and sought the approval of a doctor practicing at a proton centre added credence to her decision. She appears to differentiate between the type of expertise she views as credible;

“...we met with Dr X, who really for me personally, meeting with someone who
works with proton every day and who is considered a real expert, who’d already
treated children with the same condition, if it had been, if he’d said to me, ‘I’ve
never treated anyone with Medulloblastoma, erm, I think I would have been very
worried, but he actually gave me a presentation...’"
It is apparent that disagreements which arose between Hazel and her son’s primary team of doctors were mainly due to different treatment outcome goals. For Hazel, the side effect profile of treatment precedes its efficacy to treat Nick’s tumour, since she did not want her son to suffer from and live with the detrimental effects of X-ray radiation. Rejecting the views of the primary team of doctors, Hazel’s view of proton treatment and decision to opt for this were informed by her own research and affirmed by the views of those who she regards as the real experts on the matter. Hazel also consulted with other users of PBT; two of these families had raised funds for their child to be privately treated with PBT, where one of them had the same diagnosis to Nick. Other parents’ expertise and experience about treatment and disease therefore informed her view of treatment and aided her in the decision-making process. Additionally, having consulted with families who were already at the treatment centres, she was assured that it was the right place for her family, and was satisfied with the decision to take her other son with them to America; earlier in the interview she had mentioned her concerns about Nick’s older brother’s schooling abroad.

Hoping to give their son a better quality-of-life and reduce his chances of developing secondary side effects was also motive for Natasha and her husband, the other non-NHS family included in this study, to raise funds for their son to be treated with PBT. Natasha’s son was diagnosed with a rare, and fast-growing, type of tumour. Having had surgery and undergoing his third round of chemotherapy, the option of radiotherapy was brought up by his medical team where they recommended the use of conventional radiotherapy. Informed by their friends however, who had supported the family throughout their ordeal by collating information for them about Ryan’s diagnosis, the option of PBT was raised by Natasha and her husband. According to Natasha, their team of doctors were open to the idea of proton therapy explaining that it would increase Ryan’s chances of having a better quality-of-life and therefore supported their
application to the decision committee. Ryan was rejected by the panel however, based on the fact that ATRTs are not included in the list of eligible tumours and that either type of radiation would not increase his chances of survival. In Natasha’s view, the panel’s approach towards making this decision was problematic;

“...we didn’t think it’s fair, because they didn’t look at the case, they just looked at a number, a name, I don’t know, they didn’t look at him as a person, as a case...”

Aware of the existence of what Natasha and her husband viewed as a better option for their son, Natasha commenced her mission to seek out a medical centre willing to treat Ryan;

“...because we knew about the better option, we wanted to go for it and at that time we started searching everywhere for proton therapy...”

These parents took on a more autonomous and active role in decision-making for their child, in comparison to other parents, where their decision was based on a treatment choice they had introduced and proposed. For these parents, the decision to opt for proton therapy was informed by what they perceived to be a more desirable treatment outcome for their child. Hazel disputed the doctors’ objection to PBT, by stating that it would make some difference to Nick, and Natasha objected to the panel’s rejection of Ryan’s case stating that they had looked at him as a name and number, and not as a person. These parents’ decisions were informed and influenced by their own research, the input of other medical professionals, friends, as well as other users of the treatment.
Chapter 6: Parents’ Understandings of Proton Beam Therapy, and their Practices and Preferences Towards Treatment Decision-Making

6.3.2 NHS Funded Families’ Accounts; Autonomous Decision-Making Practices

For all other families involved in this study proton therapy was brought to their attention by the team of doctors involved in their child’s care, and consequently funded by the NHS. A nuance of difference which sets these families’ accounts apart from one another is the process they describe involved in reaching the decision to have proton treatment. Whilst some families talked about PBT being offered to them as an option to consider and describe the process as a choice to be made, other parents describe the decision to have proton therapy as a given, where no alternative was given by the doctors and nor considered by the parent. The focus of this subsection is on the first group described.

According to Ross and Katriona they attended the first appointment with their daughter’s consultant fully expecting chemotherapy to be on the agenda. During this meeting however, the consultant suggested that Grace may be an ideal candidate for PBT. Ross recalls having heard about proton treatment through media coverage of the Ashya King case, although his understanding of the treatment was limited at the time;

“...we went in fully expecting that they’d be discussing a treatment plan for chemotherapy, erm, when the consultant, erm, talked about proton, so that was the first we’d heard of it, I’d seen, you know, I’d read the stories and seen the stories about Ashya King, but I hadn’t put two and two together, erm, you know, when you’re seeing something, you have half an interest in so much of it being a story about a poor little boy, but you don’t sort of take the proton element into your mind because you haven’t heard of it before, erm, and the consultant said to us about, when he started to mention it as an option he said, ‘don’t believe what you read in the papers, it is, it is being funded if we feel it is the right treatment...’”
Their account is at odds with the majority of parents, where they recall a process involving an MDT (Multi-Disciplinary Team) unable to reach a conclusive decision regarding Grace’s treatment pathway. Their story is recounted below, by Katriona:

“...when we saw the consultant he actually then said, ‘actually there’s another option and I think she will be eligible, she’s just on the line for it, for proton beam therapy’, and then he told us that it would be down to them, they would have a MDT to say if she, if they want to put her forward for it, and then when they had this meeting it came that it was inconclusive one way or the other, so then it was down to us to decide if we wanted to go for proton beam therapy or the chemotherapy, obviously the consultant was heavily, you know, in favour of proton beam therapy, he even said that if it was his own daughter he would do proton beam therapy...”

Having asked them how they proceeded to make this decision, Ross explains that if Grace was to have chemotherapy, she would still likely have PBT afterwards and they did not want to put her through this. He also explains that the only reason for them to hold-off from having PBT immediately would be to allow for her brain development to advance further, “’cuz there are possible consequences with cognitive, you know like with retaining information, but, we took those chances”. Ross explains that they took those chances since they thought Grace was advanced beyond her age. He describes it as a terrible decision to have to make but thinks that it was probably the right one to make. Katriona supports this by stating that PBT is better for children, since she thinks it is less damaging:

“...proton, obviously for kids, proton therapy is much better, I mean obviously I’d say proton beam therapy is, is relatively new, the actual proton is not new, but the actual, how long they’ve been doing treatment, so they haven’t got much data
to, ... but obviously I think, obviously it's definitely not as conventional therapy,

but when they give you the worst-case scenario, I think they base a lot on

c conventional radiotherapy and I think proton therapy is much more, it's less

damaging ...”

When asked to substantiate this claim and to elaborate on what information they used to support
their decision to have proton, they explained that they relied on information relayed to them by
the radiologist and also read up on information online, from sources which they describe as

reliable;

“Katriona: we’d be going online trying to find out more information and trying to

stick to the website (the NHS website),

Ross: yes, we were not looking at sort of, websites, information on websites that

weren’t linked to the NHS or the brain tumour charity or anything like that,

because, erm, you know, you’re just scared of seeing sensationalist information

that is not really backed up and obviously we knew that those ones would be so

we stuck to those...”

Taking a similarly precautionary measure to Katriona and Ross, Jennifer explains that she did
not ‘doctor google’ information about PBT and made use of the booklet given to her by the
doctors. Whereas her husband was aware of proton therapy, through the media coverage of the
King case, she explains that she had no prior knowledge of the treatment;

“Interviewer: you said you’d never heard of it, how did you approach that?
Jennifer: Erm, my husband knew loads about it, he knew all about Ashya King, I had no clue, but he knew all about that and they gave us some really useful booklets as well, erm, which was from the NHS, which was really helpful and that kind of gave me the ins and outs of what it would be, but I think for my husband, he’d already heard about Ashya King and he understood about the impact of radiotherapy and he basically said, ‘yeah, it’s a no brainer, it really is a no brainer’, but I hadn’t got a clue, so, I didn’t doctor google, but I did look on the internet to find out what it was, but that booklet was really really useful…”

Repeating her husband’s words, Jennifer describes the decision to have PBT over any other form of treatment as a ‘no-brainer’, where once again the side effect profile of treatment is a major influencer. Informed by the doctors’ explanations of the treatment, her husband’s prior understanding and her own online research and the NHS information booklet, Jennifer confers that PBT is the better option and agreed with the doctors’ recommendation;

“…they (the doctors) said, ‘oh you can go for proton therapy’, well, you know, what’s that mean? And they said, ‘well it’s, it doesn’t go any further than you know, the site, and the after effects and the future effects are less’, so it’s kind of a no brainer really, you know, of course that’s what we’re ‘gunna go for, we’re not ‘gunna put him through something if we can have this other option instead, so It was a bit of a no brainer…”

Jennifer, Katriona and Ross emphasise the importance of accessing information about this new treatment from credible sources, rather than ‘doctor googling’ or accessing possible sensationalized information. Despite the plethora of information available online, these parents described themselves as having relied on information produced and/or approved by the healthcare professionals. This draws attention to the important role that patient information
leaflets play in informing users’ views of treatment, and also hints at what some parents regard as ‘responsible’ behaviour in the context of decision-making for their child.

Sixteen of the 19 NHS-funded families describe a similar scenario in which the option of proton treatment was given to them by their child’s doctors, and they were tasked with considering their options before committing to a firm decision. In these instances, the decision to opt for PBT can be described as a joint venture between doctor and parent(s), although some families describe feeling pressured and steered, by the doctor, towards PBT. Informed about the option of PBT, these parents relied on different sources of information in order to reach a decision; information accessed by the internet, clinicians’ views and input, as well as other families and patients treated with proton therapy were found to have played a role and influenced these parents’ decision about PBT. In some instances, parents’ familiarity and unique knowledge of their child was also factored into this decision-making; Ross and Kattriona considered their daughter’s development in order to choose between chemotherapy and PBT.

6.3.3 NHS Funded Families’ Accounts; Passive Decision-Making Practices

As mentioned above, some of the parents describe the decision and pathway to proton therapy as a given, with no scope for an alternative treatment or room for decision-making on their behalf. This section highlights their accounts.

Daniel’s daughter was diagnosed with an ependymoma tumour as a baby and suffered a relapse before she turned five. Following her relapse, his daughter underwent two different surgeries and it was at this point that PBT was presented to him and his wife by the doctors. Daniel explains that since his daughter’s earliest diagnosis, he had partaken in various fundraising events for brain tumour research and was therefore familiar with proton therapy. He describes
being surprised by the recommendation for his daughter, but took it as a given that she required this treatment;

“...it was explained to us that if she didn’t have Proton Therapy, erm that she’d be having, that she’d instead, you know, potentially have, you know, conventional radiotherapy at X, erm, but the advantages of the Proton Therapy was that, you know, potentially there’d be less damage to the, to healthy tissues, so might result her in having a better quality-of-life, erm, I was very mixed up I think in terms of what I personally wanted her to have, erm,... but then the way it was portrayed was that the radiotherapy that she might have in the UK, would be so much more damaging, erm, that, erm, that really proton was the only, the only option,...”

Kim and Tom echo a similar experience and explain that PBT “wasn’t an option- it was a given”. Their daughter, Chelsea, had been diagnosed and treated for a Pilocytic Astrocytoma tumour at the age of five, but had relapsed at the age of 10. They explain that following the completion of her first surgery, they were preparing for the second surgery when the doctors decided against this and suggested that PBT would be more beneficial for her. When I asked how they responded to this and whether they researched this newly recommended treatment, Kim explains;

“...we did research it a little bit, mostly, we did have quite a lot of the information through the medics, erm, I don’t know if I researched it massively ‘cuz I think I felt, maybe we both did, that there wasn’t really an option and so we just had to go for it anyway and trust that they wouldn’t have recommended it if they didn’t think it would, you know, be successful and be the best available treatment for her...”
Kim and Tom trusted their doctors’ recommendation despite being made aware of the limited long-term research and evidence available;

“Tom: they said obviously, in terms of the, erm, side effects long-term, that they did say to us that ‘cuz it’s quite a new treatment there isn’t the research there for it, so they said, initial signs are all very good for it, but going for, what could happen say in 10, 20, 30 years down the line, they did explain that there isn’t really the research there to be able to tell us,

Interviewer: Yeah,

Tom: yeah, so there was that unknown to us wasn’t there?

Kim: yeah,

Tom: but in terms of being less intrusive and better for her, that helped while going through the treatment, sort of a lot better option for her”

Kim later adds that PBT would potentially do less long-term damage to her brain, than traditional radiotherapy.

Echoed in both these accounts is the parents’ trust in the doctors’ judgment and recommendation. Kim trusted that the doctors would not have recommended PBT if they did not think it best suited for their daughter, and Daniel repeatedly alludes to his faith and trust in the doctors, from the time when his daughter was first diagnosed. These parents are complacent and accepting of the doctors’ recommendation, albeit their mixed feelings about treatment and
awareness of PBT’s shortfalls. PBT is presented to them by the doctors as the only option and these parents are accepting of this fact.

Heather and Graham also explain that proton therapy was portrayed to them as the treatment necessary for their son. Charlie was aged 13 when he was diagnosed with a Craniopharyngioma and underwent surgery in order to drain the tumour. Following the completion of his surgery, his parents were told that he would be monitored regularly until he reached the age of 16, which is when he would require radiation therapy. In the extract below, Heather recalls the MDT making a U-turn however and referring Charlie for PBT soon after surgery;

“...they said to us, that’s fine, you know, we’ll monitor you, you won’t need any radiotherapy until he’s 16, he was ten, 11 at the time, erm, and then we went back to see them in the March and they said, ‘you need to go for proton therapy, it just came out of the blue, we didn’t even know what proton therapy was, we just sat there and went, ok, ok, and also because it was his brain surgeon, who didn’t really know anything about it, but they’d obviously had an MDT meeting and so decided that’s what we needed, and you’re scared, because you don’t want to say, ‘oh my god what is it, how we ‘gunna cope?’, ‘cuz you worry they won’t let you go, so you just go, ‘yeah, yeah, fine (laughs)...”

Overall, Heather and Graham’s account is at odds with the majority of interviewees, where they do not view PBT in the same favourable light as the other parents. Heather explains this below;

“yeah, unfortunately, um, I don’t know if I’m a great fan of proton, I have to be honest, it’s done some longer-term damage with Charlie, erm, it’s caught part of the brain which has his working memory...”
When I probe them further, they explain that Charlie is having issues with his pituitary gland and binasal vision, is struggling with diabetes and experiencing major issues with memory loss, which is why they are not in favour of PBT. However, they both repeatedly state and explain that proton treatment was described to them as an essential treatment for Charlie and they therefore never questioned it, for fear of it being taken away. They also claim to have been amongst the top first 50 families to travel to America for treatment, and therefore lacked access to any information other than the NICE guidelines about PBT funding.

Having highlighted the different treatment pathways and experiences regarding access to PBT, it is clear that some parents take on a more active role in matters related to their child’s treatment. Some parents describe the process as a joint venture between self and doctors, where they were given more autonomy and power to choose between different treatment options, prior to settling on PBT. Other parents describe a different experience, where PBT was presented to them as the only option available to their child. These parents trusted that their doctors would not recommend a treatment if it were not deemed necessary, and also mention fear of challenging this opinion, for fear of treatment being taken away.

The next section goes further by looking at parents’ practices and preferences towards treatment decision-making in general.

6.4 Parents’ Preferences Towards Treatment Decision-Making

As parents spoke about the various modes of treatment used as part of their child’s treatment protocol, i.e. surgery, chemotherapy, radiation therapy, some described taking a more active role in the decision-making process, or at least trying to. Others described encounters and
experiences best fitting within a passive model of decision-making, where they described situations where treatment decision(s) were made for them, by the child’s doctors; these parents were largely complacent and accepting of this practice. This section looks at parents’ preferred practice towards decision-making involving their child’s medical care and treatment.

Research has found variability in how parents view and negotiate their responsibility, and that of the doctor, in decision-making concerning their child’s medical treatment (Lipstein et al 2012, Kilicarslan-Toruner and Akgun-Citak 2013, Pyke-Grimm et al. 2006). Parents’ views about decision-making have been categorised into three groups; the physician has authority, the parent has authority, and the parent and physician share opinions and make decision together. A shared model of decision-making, between clinician and family is viewed as the ideal (Lipstein et al. 2012). Trusting and communication with healthcare professionals, economic factors, resources and expectations of the healthcare team and the illness situation, are factors thought to affect the decision-making preferences and practices of parents. Recognising their own knowledge deficit in comparison to the doctors’ expertise, some parents prefer their doctor to guide medical decisions involving serious situations, especially when there is a high level of threat to the child (Pyke-Grimm et al. 2006). However, as parents acquire more knowledge about their child’s condition, they become encouraged to take on a more active role in treatment decision-making (Lipstein et al. 2012, Pyke-Grimm et al. 2006).

The first half of this section is focused on parents who share the view that doctors know best and are better adept at making decisions for their child. Whilst some parents spoke of a desire to have been more involved in the decision-making, they acknowledge that they are not in a fit position to do so, and that the doctors know best. Following this, the experience of parents who seek a more active role and responsibility in decision-making are explored.
6.4.1 Delegating and Evading Responsibility

Nearing the end of my interview with Rochelle, I ask whether she has experienced any disagreement with her daughter’s medical team, throughout active treatment and beyond. Her response is as follows:

“It’s interesting, erm, I think when you’re on, I think when you’re on the whole journey, you are very much taken into the hands of the clinicians and you do sort of follow what they say, given that they’re the experts and so on and fortunately for us at the time it was a topic that we knew very little about, so we were prepared to take their lead, erm, I don’t think as a parent you do have that much influence, erm, within the treatment about, erm, your views and so on, at least we haven’t so far, erm, my husband was very concerned about the X-rays and them hitting the brain and that side of things, so he did voice his views quite, erm, quite strongly to the Americans when we were told it was ‘gunna hit the brain, because she’d gone in for her first treatment and we were a bit shocked by what they were going to do, erm, they definitely listened, but I don’t think there was ever a question things would be changed based upon what we were saying, but then I think that’s probably right because they’re the experts in this, we knew very little, erm, perhaps if it was a relapse or if, you know, we were further down the line, 5 years or so and we’d seen more, maybe we would kind of think differently and have more of a say on what we thought about the type of treatment and what was worth it and what wasn’t, but, you know, we were in our first year, so, we tend to go with what the experts say, but I don’t think we feel that we have much of a voice on the treatment, but then, we’re not the experts or medics, erm, so we do kind of follow their lead, that’s an interesting thing.”
In the above extract Rochelle describes herself and her husband as passive and willing to take the doctors’ lead, in matters concerning their daughter, Katie’s, medical care and treatment. This passive role initially appears unproblematic, given that the doctors are the experts and herself and her husband’s knowledge of the topic is limited and inferior in comparison. However, recalling an anecdote where her husband was vocal in his concerns about the use of X-rays, given the risks of this to Katie’s brain, Rochelle depicts herself and her husband as attempting to utilise the knowledge they have acquired, about the different treatments and their side effects, to exercise some ‘agency’ in matters concerning Katie’s medical treatment. Yet, by reaffirming the expertise of the doctors, and their own limited knowledge, Rochelle justifies herself and her husband’s overall role as passive participants to the encounter. There is a nuance of tension however, where Rochelle’s position on responsibility and involvement in decision-making shifts, as she postulates a future scenario where herself and her husband would exercise some influence and take on a more active role. Rochelle recalls herself and her husband’s lack of experience and knowledge during the first year of Katie’s treatment, and compares this to the present and a possible future scenario requiring them to make such decisions. In this scenario Rochelle feels they are now both better equipped and informed to think and approach matters differently. In a further excerpt from her account, detailed below, Rochelle describes herself as having acquired knowledge on a par with the medics, which enables her to now think matters through, rather than “go[ing] with the flow”:  

“I think we were so shocked by the whole thing as it unfolds, that you do just go with the flow a little bit, and now I think we think about things more, erm, but I mean I know that some people for example, it’s a big learning curve for parents, there’s so much information and you have to learn almost how to be bit of a medic yourself…”

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Ultimately however, Rochelle recognises an imbalance between parent and medic based on expertise, which prevents them, as parents, from having much of a voice in matters concerning their daughter’s treatment decisions. Given that the doctors are experts, Rochelle is content with entrusting responsibility for her daughter to them. In fact, her closing words of advice to fellow parents, who find themselves in a similar position to herself, is to take a step back and listen to the doctors;

“...listening, taking a step back, trying to go with the flow, not over thinking things
and just putting your child, put your child first and do everything that you can to
make sure that they’re getting the best, erm, treatment…”

Overall, there is tension is the way Rochelle views and describes her role and position in decision-making concerning her daughter, where her stance on the matter shifts across her narrative. The limits and restrictions she speaks of are fitting with a paternalistic model of the doctor-patient relationship, which stipulate the medical professionals’ expertise (Lepstein et al. 2012). Coupled with this is her view that agreeing with the doctors constitutes responsible parenting (Lupton 2013, Nelson et al. 2013). There is tension however, where she describes herself as almost becoming a medic and willing and able to take on a more active role in decision-making, now that she has acquired this knowledge. This is similar to findings reported elsewhere (Lipstein et al. 2011, Pyke-Grimm et al. 2006), about parents’ views shifting with the acquisition of knowledge and experience; parents’ expertise is explored in the proceeding chapter.

Whereas Rochelle was not assigned responsibility to make the decisions about her daughter’s treatment and was content with this, given that in her view the doctors are the experts, some parents described being given treatment choices and yet struggling with the responsibility to
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decide, for the very fact that the doctors are more equipped to make such a decision. Rosalin and Claire, were assigned with responsibility to choose between the use of PBT or X-rays as part of their child’s treatment protocol. The excerpt below is from my interview with Rosalin. Rosalin had explained that following her son, Mason, being diagnosed and undergoing surgery, the oncologist then laid out the follow-up radiotherapy options, i.e. X-ray radiation therapy or PBT, that he would have to undergo.

“Interviewer: Uhmm, so was the decision given to you to choose?

Rosalin: Yeah, I mean it was quite, because you know, as parents you’re kind of, you know, we’re not medical experts, you just want the best for your child, erm, and they didn’t actually say we would rec, they don’t say we would recommend this, erm, but what they do say is that, you know, the effects of both of the treatments would treat the tumour the same, erm, but obviously with the proton there’s less damage to surrounding area, erm, so we sort of took that away and had a think about it, but kind of, although I wanted her to say proton is the best thing for him, kind of I guess that’s a bit naïve and she wasn’t ever really going to say that, we kind of came away and talked about and looked a bit, you know, just did a bit of research and just decided that yeah we were ‘gunna go for the proton”

It is apparent that Rosalin was not entirely at ease with the responsibility assigned to herself and her husband, to decide between X-ray or proton radiation, since in her own words, they are not “medical experts”. Stating that “you just want the best for your child”, Rosalin explains that she would rather have had the doctors make the decision or make their recommendation explicitly clear, since they are more adept at doing so. Rosalin and her husband ultimately draw from the expertise relayed to them by the doctors and the information they sourced form their
own research, in order to make the decision to opt for proton therapy. A similar view is shared by Claire in her account, where she recalls feeling uncertain and overwhelmed when given the responsibility to decide whether her daughter, Emily, should have PBT or X-ray radiation therapy. Adding to Claire’s uncertainty was the fact that Emily’s surgeon and oncologist were each in favour of a different treatment.

“...that was the only sort of part I felt was badly managed, ‘cuz I felt they should have got together, ‘cuz they are kind of a team and they should have made that decision and come together, which they finally did, ‘cuz I actually sent an email and said look, I’m really disturbed by all this uncertainty, we don’t know what to do, we don’t know, you know, we don’t know what we’re doing, we’re just the patient and they finally sort of came to an agreement that, yes, ok, it probably is the best, and that’s what we did,...”

In the segment above, Claire describes both herself and her daughter as “just the patient”, which in her view, means not knowing and not being equipped to decide on what to do. With this view in mind, Claire explains that the decision about treatment should be made by the team of doctors involved. It is evident that Claire has clear notions of what constitutes doctor and patient/parent expertise and how this ought to be utilised. In the end, Claire evades the responsibility to decide and asks Emily’s team of doctors to make the decision for them.

The view that doctors are the experts and possess forms of knowledge that the parents (and patients) do not have, informs and shapes these parents’ preferences and assessment of their role and responsibility towards their child’s treatment decisions. The view that doctors are experts means that parents who were given the onus of decision-making about treatment felt inadequate to do so and would rather relinquish this responsibility to the doctors, who they view
as the experts in this scenario. For parents, such as Rochelle, who were not given an opportunity to practice some choice, this was unproblematic again given that the doctors’ expertise was regarded as better suited. Tensions emerge however, where experience and knowledge acquired about their child’s condition and treatment shifted some parents’ stance; Rochelle compared her lack of experience during the early stages of her daughter’s illness, and compared this to now and explained that she was more willing and able to take on an active role in decision-making. Notions of good parenting practices also permeates these parents’ talk; taking ‘putting your child first’ means taking a passive role and going with the flow set out by the doctors.

6.4.2 Seeking Responsibility

For the above-mentioned parents, the view that doctors are the experts meant that they were willing and content with relaying the responsibility for their child’s treatment decisions to them. Whilst this view also holds true for Jennifer, this participant explains that she sometimes struggled to merely accept and come to terms with the medics’ decisions;

“...I do find that whole decision-making things quite difficult, and like I say, when they changed his chemo I really felt a bit lost as to, well, ok, you’re telling us that you’re changing the chemo, but you’re not telling us, apart from it’s not working, exactly why you’ve chosen the ones that you’ve chosen, that’s very very difficult, for his, the bits that I can control, I do tend to control, so, how long we’re in hospital for, if I say we’re leaving in an hour we’re leaving in an hour, because we’ve both had enough, but I think for medical decisions, although I’m a bit of a control freak, you don’t often get given a choice, erm, and I think, ’cuz they know, they know what they’re talking about, you do feel a bit lost, you can’t make a
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Jennifer struggles with the fact that she is not given a choice within her son, Wilson’s, medical decisions, but is accepting of this given that the doctors have the knowledge necessary to make informed decisions. In her view, this knowledge is paramount, since “you can’t make a decision without the knowledge.” Nevertheless, Jennifer describes feeling lost and finds the overall expectation that she merely accepts the doctors’ decisions difficult. In the above extract she refers to doctors’ decision to change Wilson’s type of chemotherapy, without offering her an explanation for why this move was made. Elsewhere she refers to the changes made to Wilson’s medications, and her difficulty to understand and accept these changes;

“... you look at the top (of the information sheet) and it says, ‘this drug is used to treat testicular cancer or breast cancer, or you know, lung cancer’, and you think, well actually my son’s got an RMS and he’s paediatric, so why have you chosen that? Why is this one that they’re saying is generally used for these treatments, why is it being used for, you know, a 10-year-old boy?”

Jennifer speaks of ‘control’ and trying to recast control where she can; for instance, she talks about controlling the duration of hospital visits; “the bits that I can control, I do tend to control”. There’s a limit to the control she can exhibit, and she is aware of this. In an effort to regain a sense of control over the situation, Jennifer suggests that she needs the doctors to provide her with information about the course of treatment they are choosing for Wilson. She also explains that she relies on her sister, who she describes as her google-gatekeeper to gather information for her. Whilst Jennifer shares the view that her knowledge is not on a par with the
doctors’ and recognises that her restrictions within treatment decisions are based on this reasoning, she recasts and reclaims the onus of responsibility for her son’s treatment decisions by ensuring that she has the knowledge and information necessary to keep the doctors in check. Having initially stated that she has no choice in treatment decisions Jennifer’s stance changes, in the closing lines of the segment above, where she uses the information and owns responsibility for ensuring the right decisions are being made.

Nuances of struggle over the responsibility and contradictions within parents’ preferences and practices surroundings treatment decisions were evident in the majority of accounts. Linda’s account is one such account. The extract below, albeit lengthy, is a good example of this;

“...the big dilemma with this particular kind of tumour is that, erm, if you try to remove the entire thing you can damage the hypothalamus, you can damage the pituitary, you can, you can leave more damage than doing good, so there was, I suppose different thoughts was how much of the tumour should be removed and how it should be removed, whether it should be removed by craniotomy, whether it was possible to remove it transsphenoidally (sic) through his nose, and thankfully, erm, there was a multidisciplinary committee which determined the best course of action for Curtis, but it was still a very harrowing process for us to feel also that we didn’t really have a choice in the matter, that really the decision would be made for us, erm, and that was made pretty clear, not that we were ever saying that we would only want to do things one particular way, and we also felt very out of our depth, erm, you know, we realised we weren’t in the best place to decide how the surgery should happened and how radical the surgery should be, but also, you know, we realised we’d be the ones to pick up the pieces if it didn’t go the way you know everyone hoped, and we were told that if the entire thing
wasn’t removed that he would likely need proton beam therapy, which is you know, which was explained to us as being, you know, like a radiation, well radiation treatment but much more targeted…I remember having a conversation with Curtis’s endocrinologist and saying, so the, erm, you know, I was basically saying, you know, perhaps it’s better that they actually take out and then he won’t need radiation and she said, ‘well we will decide what is best for him’, and it was really, it dawned on us that the decision is not actually ours to make, erm, and that, in a sense left us slightly uncomfortable, but we didn’t feel equipped to, we could see that there wasn’t a perfect answer anyway and we were the least experienced people in the room, erm, and so we trusted our doctors…”

In the extract above, Linda initially sets out the dilemma facing Curtis in terms of what course of action would yield him less long-term damage; removing the tumour via a Craniotomy\(^{10}\) or Transsphenoidal hypophysectomy\(^{11}\). Listing the risks attached to the removal of the tumour, Linda is thankful that the multidisciplinary committee was there to determine the best course of action. Yet in parallel to this, she recounts the struggle she and her husband had with accepting the fact that such difficult treatment decisions would be made for them, without their consultation; this is similar to Jennifer discussed above. At one level, Linda appears accepting of the situation, given the fact that herself and her husband were not equipped nor experienced enough to make such a decision. She also speaks of the trust she has in the doctors to make the right decision. Her struggle with comprehending this order of practice remains though, where she tries to carve out her role and responsibility as a parent in the context of her child’s healthcare; whilst stating her difficulty with accepting her marginal role, she also states that she had no intention of stating whether surgery should be performed in a particular way.

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\(^{10}\) A surgical procedure where the bone flap is temporary removed from the skull, (NHS 2017a).

\(^{11}\) A surgical procedure which accesses the brain through the sinus, (UCLH 2018b).
Alluding to the medics’ informed decision-making, Linda simultaneously stipulates that as parents they would have to contend and live with outcome of the decision, if it was to yield an undesirable outcome. In an effort to claim some of the lost agency, Linda recalls an anecdote where she sat down with her son’s doctor and proposed an alternative treatment plan, which would not require radiation therapy. Ultimately however, Linda states that herself and her husband came to the realisation that they are not equipped nor experienced to make such a decision. This resonates with Rochelle’s account in the opening section of this chapter, in which despite her struggle with the order of practice, she framed herself as willing to entrust the responsibility for her daughter’s treatment decisions to the doctors, since they are the experts and she had little experience and knowledge.

In a later segment from her account, Linda speaks about a range of other health issues that Curtis has contended with and how she and her husband have approached medical intervention for these. In this account, Linda’s approach towards decision-making is at odds with the segment discussed above. Whereas in the example above, Linda spoke of her trust in the doctors and their competencies, in the section below, her tone shifts where she speaks of unpacking the doctors’ plans, questioning their opinions and taking on a more active and vocal role in matters concerning Curtis’ medical care.

“...he’s had other surgery, we’ve sought different opinions ‘cuz we know surgeons are very sure of themselves but they all have different views, so you need to speak to them and you know, not just rely on one person’s opinion, and, and, try the, you know, kind of pick to pieces whatever plan is made, erm, but, yeah, challenging and questioning, you have to, I think you have to be your child’s advocate, because, erm, you know, I just don’t think it’s a sensible approach to just give, give the decision-making in respect of your child away to anybody really,
Similar to Rochelle, Linda’s stance and view on decision-making and the role of doctors and parents shifts in the course of her narration. At the start of her narrative, although she struggled with her passive role within decision-making, she accepted that the doctors were better equipped to make decisions during the early phases involving Curtis’ condition. As they have progressed in this journey however, she reclaims some onus of control and responsibility by challenging the doctors’ recommendations and seeking multiple views.

Another parent who challenged the notion that doctors know best, and sought ‘agency’ in decisions concerning their child’s treatment, was Hazel. Hazel is one of the two non-NHS participants who took part in this study; her case was discussed in detail earlier in this chapter. In the following extract, Hazel is recalling the aftermath of her son, Nick’s, diagnosis and how he came about to be treated with protons;

“Hazel: you know, having to make decisions at that point that are life impacting, life changing, lifesaving, all of those, and you, they tell you, ‘you’ve only got a very little amount of time and this is what we recommend you do’, erm, and the recommendation was, erm, photon radiotherapy and chemotherapy, and potentially another surgery to see if they could remove a little bit more, ‘cuz they’d left quite a bit behind, you know, it’s a question of what’s safe to take away, erm, with a Medulloblastoma, as it turned out to be a Medulloblastoma, it would have been better to get rid of everything, erm, so, according to the neurosurgeon, he said he’d left a considerable amount behind, we then went off and started to get
second opinions, so we got four opinions, probably totally over the top, O hospital, they were not happy with us, because they said, ‘the more opinions you get, the danger is that every opinion is different and you know, then you’re more confused’, they were very set on their photon therapy, chemo therapy, potentially another surgery.

Interviewer: Uhum, what motivated you go for different opinions?

Hazel: We felt so helpless and I think both my ex-husband and I, the way we work is, erm, I’m quite academic in my background, I need to understand, if I approach a problem, I need to understand everything about it, as much as I can, and the problem for us was that we didn’t have much time, I couldn’t do, I couldn’t spend a year on research unfortunately, but, you know, we had a few days, Nick was not in a good way, so they wouldn’t have touched him anyway until he’d at least recovered physically, erm, so we had a little bit of time to do some research and we, we wanted experts, we needed to find people that, that knew something about this subject that we knew nothing about, erm, and we didn’t know, I mean, where do you go? I mean now, looking back, I’d probably have asked other parents that have been in the same situation, but you don’t know anyone, you have no connections in that realm and it’s very difficult, the only way for us was to reach out into our own network and find people that were experts’’

Hazel’s chooses to challenge the primary treatment recommendation and she seeks out multiple other medical opinions; from people she views as experts. In her account, Hazel speaks of the pressures and expectations she felt was placed on her by the doctors, to comply with their recommendations, and recognises that her approach to seeking out four different professional
opinions was out of norm. But the way she manages her account is to suggest that in fact by ignoring the primary team’s recommendations and seeking these expert opinions, she is acting in the best interest of her child. In this way she is legitimising her behaviour in the context of the doctor-patient encounter.

6.5 Summary

Answering the research question, ‘How do parents view and understand Proton Beam Therapy?’ , this chapter has explored the ways parents think of and understand PBT, a new type of radiation therapy. It has been demonstrated that widely held negative perceptions of radiation therapy prefigures some of these parents’ understanding of proton treatment. Despite the newness of proton treatment, these parents’ views of treatment were informed by wider discourse associated with the radiation nature of therapy; this led to negative perceptions and uncertainties about its use. This finding is consistent with previous research which has found that misconceptions surrounding radiotherapy are thought to heighten patient anxieties and impact decision-making (Williams et al. 2017, Woodman 2013, Halkett et al. 2012 and Owens et al. 2003). Parents portrayed themselves as putting these negative associations aside however, as they developed their understanding of treatment and became aware of the targeted nature of PBT and its consequent ability to reduce treatment side effects. Juxtaposing proton treatment with the conventional mode of therapy highlights the features of PBT and adds to the allure of the technology. This leads to the view that PBT is superior to conventional radiation therapy, albeit the lack of long-term evidence and research. The comparison model adopted by parents is in line with the approach adopted within the documented material, analysed in the previous chapter.
This chapter has also highlighted sources of information and factors which had influenced and contributed towards parents’ views of PBT, and decision to opt for this treatment. Information specific to the treatment, and information in relation to its access were sought and considered. Some parents actively sought out information and were found to have relied on this in order to formulate a view of treatment and decide whether they think it is suitable for their child. There was a note of caution by parents who described taking extra measures in order to ensure that the information they sought and used was reliable; Ross and Katriona for example described avoiding sensationalised news and reports and sticking to the reliable websites, as well as information relayed to them by their radiologist. Referring to the case of Ashya King, these parents explained that it is important to make sure the information they read about the treatment comes from credible sources. Parents also relied on information relayed to them by the doctors to help them understand the benefits of treatment and make a decision, where some parents made a distinction between the types of medical professional from who they sought information and approval from; in these instances, the input of the experts from the proton centres were valued and sought. The experiences of other patients and families were also pursued, with parents relying on information from patients diagnosed with the same disease to their child, as well as patients who had undergone PBT. When making a decision to have treatment, some parents also relied on their own unique knowledge and understanding of their child to decide whether it is suitable. The travel element involved in accessing PBT was also mentioned by some parents, although this did not appear to play a big role in their decision and was not explored extensively in this chapter. These parents mentioned having relied on information from families who had been out to the proton centres, in order to decide and make sure it is appropriate to take their whole family. Findings to emerge from this research are in line with other studies which list doctors’ recommendations, family, and other patients’ experiences as bearing influence and guiding parents’ decision-making (Lipstein et al. 2012).
In this research, a distinction was made by some parents between doctors from who they sought guidance from. Given that PBT is relatively new, some parents sought the opinion of clinicians who had experience and expertise on the matter.

Despite the NHS document alluding to the limited resources and available evidence about the use and efficacy of PBT, most parents were satisfied with the decision made about their child receiving proton treatment; the side effects were largely at the forefront of the decision-making discussion and rarely any mention was made about the overall outcome of treatment on the child’s tumour. Within the non-NHS participants’ accounts, it appears that the conflict which arose between parents and doctors was due to their different preferences and views regarding the outcome of treatment. It was demonstrated that for one mother, the side effect profile of PBT preceded its efficacy to treat the tumour.

With the aim of answering the research question, ‘How do parents manage decision-making involving Proton Beam Therapy?’, this chapter examined parents’ practices and preferences towards decision-making involving their child’s overall treatment plans. Parents’ preferences and practices varied with some describing taking on an active role and their desire to be more involved in decision-making, whilst others described being content with their passive role and allowing the clinicians to lead. In some instances, parents’ stance changed, and they alternated between passive and autonomous roles. Experience and the acquisition of knowledge throughout the child’s condition appeared to play a role, where some parents reflected on their initial lack of knowledge at the start of their child’s illness, and compared this to now and the knowledge they have acquired about treatment and disease. In line with other research in the field, these parents’ decision-making practices varied and evolved (Lipstein et al. 2012, Pyke-Grimm et al. 2006). With the view that doctors are the experts and therefore more adept to
make treatment decisions, some parents were content with their passive role and others described wanting to relinquish the responsibility assigned to them and leave decision-making in the hands of the clinicians. This view shifted however, when parents gradually became familiar with matters related to their child’s illness.

Parents appear to negotiate their role in the context of their child’s clinical encounter, where ideals of good practice permeate talk about their role and responsibilities. Based on the view that doctors are the experts and know best, some of these parents relinquish the responsibility and are content with the doctors leading decisions; these parents legitimize their behavior by suggesting that they are acting in the best interest of their child. Additionally, parents’ motivation to seek information, and explore options, is based on the need to ensure the right decisions are being made, by themselves or the clinicians, for their child. In these accounts there are also nuances of what constitutes good parenting in the context of their child’s illness.

By weaving detailed accounts of these parents into each section, this chapter has aimed to provide a detailed introduction to the parents and their different and unique experiences. The next chapter is focused on parents’ knowledge and expertise.
Chapter 7: Navigating the Child’s Illness and Proton Treatment through Parental Expertise

7.1 Introduction

This chapter explores parents’ knowledge and work, deployed in the care and management of their child’s illness and treatment experience, and treats this as expertise. This chapter aims to answer the following research questions, posed earlier in the thesis; ‘What types of specialist expertise do parents of children treated with PBT possess?’, ‘How do parents acquire their specialist expertise?’ and, ‘What do they use their specialist expertise for?’

The notion of expertise and the expert patient is contested, where some scholars suggest that experience alone does not qualify as expertise (Prior 2003). According to Prior, patient or carer expertise is limited to their experience and what is not experienced is not known, therefore their expertise does not reflect the broader aspects of the illness. To qualify as an expert, it is suggested that in depth knowledge and training of the subject matter is necessary (Fox et al. 2005, Prior 2003). Prior calls for clarification of the use of the term ‘expert’. Collins’ (2014) framework of expertise is a helpful tool for conceptualising expertise. This framework of expertise has previously been employed in order to examine and treat chronic patients’ knowledge of their condition as expertise, where Green (2017) has demonstrated how prostate cancer sufferers are in possession of different forms of specialist prostate cancer expertise; Green’s research has been seminal to the development of this chapter.

Utilising Collins’ model of expertise, this research situates parental knowledge, related to their child’s illness experience, as expertise. This chapter demonstrates the way parents, through
their experience of caring for and managing the child’s illness, develop niche pockets of expertise in relation to their child’s disease, its treatment and overall experience of illness. In section 7.2, parents are demonstrated to be in possession of ‘contributory’, ‘interactional’ and ‘special interactional expertise’. Following from this, how these parents come to possess these expertises is explored; online support groups are found to play a key and important role, where parents are found to especially rely on the expertise of fellow parents, accessible in these groups. Next, in section 7.4, examples of parents sharing their acquired expertise with others is explored. Parents’ motivations to acquire expertise are explored in section 7.5, where it is found that the impetus for control of the situation involving their sick child and moral imperatives of good parenting are factors which are thought to influence parents’ acquisition of expertise. Finally, factors thought to facilitate the acquisition of expertise are explored. The chapter ends by providing a summary of the findings.

### 7.2 Parents’ Expertises

In this section the different types of specialist expertise, which parents were found to possess are explored. Applying Collins’ (2014) framework of expertise to parents’ knowledge and work, parents were found to possess contributory and interactional expertise, as well as special interactional expertise.

#### 7.2.1 Parents’ Contributory Expertise

Contributory expertise is developed with practical experience and is likened to an apprenticeship. One becomes a contributory expert through experience and by learning from other experts and picking up their skills and techniques. Collins (2014) has previously given
the example of chronic illness patients, where he suggests that they are experts by virtue of their experiences. Elsewhere, Green (2017) suggests that prostate cancer patients can be considered to have contributory expertise by merit of the knowledge they have developed through their experience of having the illness, its treatment and associated conditions. Through their own experiences of the illness and through interacting with other experts, i.e. medical professionals and patients, chronic illness patients develop contributory expertise (Green 2017, Collins 2014).

Having a child diagnosed and treated for a tumour has equipped many of the parents interviewed in this study with a range of knowledge, which can be clustered under the group of ‘contributory expertise’, otherwise known as experiential expertise (Collins 2014). Through their experience of caring for and managing their child’s illness, parents were found to have developed knowledge about their child’s tumour, its treatments as well the range of associated conditions and side effects, and how to manage these.

In her account, Kelly describes how she has learnt through experience to manage different aspects of her daughter, Zara’s, illness. Kelly notes that Zara’s experience of cancer and its treatment has been a learning curve and uses Zara’s experience of chemotherapy to demonstrate this. Zara has had multiple rounds of chemotherapy prior to, during and post PBT.

“...the first chemotherapy was the worse one ‘cuz we didn’t know what to expect, it was a learning curve for us, so, I mean she got a temperature pretty much after the first one and she had a really sore mouth and couldn’t eat, but obviously we didn’t know what she’d be feeling, you know, it was our first time so we didn’t know, but then after that time, it’s been easier because we know what’s normal, what’s to be expected, erm, the danger signs and all that, so now yeah, if she has
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a sore throat, I know it’s just a sore throat and I keep an eye on her temperature,

but yeah, we’re confident, I’d know when to take her (to the hospital)…”

Recalling the experience of the first chemotherapy session, 10 months prior, and comparing that to now, Kelly explains how she has learnt to know what symptoms are normal for Zara and what constitutes dangerous, and how to intervene and manage these. Through her experiences involving Zara’s chemotherapy treatment, Kelly has acquired contributory expertise related to her daughter’s bodily experiences of illness and its response to chemotherapy.

Kelly also describes having learnt to flush her daughter’s Intravenous (IV) line and change her dressings, and talks about having acquired ‘a lot of medical knowledge’ which she, and her husband, previously did not have;

“… I’ve learnt how to do her line flushes, just so that, it saves us an extra trip to the hospital, so we’ve changed dressings and things like that, yeah, a lot of medical knowledge now we didn’t have before, Zara has a lot of medical knowledge now too…”

Over time and through her experience of caring for her daughter Kelly has developed contributory expertise in relation to Zara’s illness. This expertise gives her the confidence to take charge and manage aspects related to her daughter’s condition, rather than resorting to professional help. Kelly has learnt through experience how to manage Zara’s bodily response to chemotherapy, but it is likely that she learnt how to flush her lines and change her dressings via the aid of a professional. Learning through other experts, i.e. other patients and healthcare practitioners, also constitutes contributory expertise (Collins 2014). One of the other participants, Rosalin, also describes having learnt to manage her son, Mason’s, different
medications with the help of a specialist nurse. In Rosalin’s own words, ‘not (being) medical’ meant that she initially did not feel adept at making decisions about Mason’s medicines. With the help of a specialist nurse however, she has grown confident in making decision about how to manage Mason’s symptoms by tweaking his dose of medication;

“…I think what we’ve kind of learnt is that you don’t, you know your child as well so you just kind of, like when they upped his, when they initially upped his thyroxine, we said, obviously we’re not medical and I don’t know that it was that, but to me it felt that since you’ve done that he’s not, he’s not so well…. we were told initially that if he’s ill or anything he has to have an extra dose of Hydrocortisone, so we’ve got an injection that he’s got to have, but then when we actually spoke to the specialist nurse, she said ‘oh it’s only really like if he had a major shock like if he broke his arm or something that he would need that’, actually, if he’s just got a cold, just double his dose, and I think, so it’s just becoming more confident with it that you know, oh well actually we can just give him a little bit more and stuff, so yeah…”

Rosalin’s account also highlights parents’ unique knowledge of their children, and the role this plays in their experiences of managing their child’s illness. Rosalin’ intimate knowledge of her son and knowing what is and is not normal for him encouraged her to raise the issue and ask for help about his medication.

Kelly and Rosalin’s accounts have demonstrated how parents possess different types of contributory expertise related to their child’s illness. These parents become experts of their child’s body and response to treatments and are able to discern what is normal and abnormal for their child. Parents develop skills which help them take on tasks which would otherwise be
carried out by a trained medical professional. Parents were also shown to have acquired contributory expertise through learning from other experts, i.e. specialist nurses, where they merge this with their own unique knowledge of their child. Acquiring these skills and knowledge are important for parents, since it enables them to take greater responsibility for the caring of their child.

Contributory expertise is experience-based expertise. Collins (2014) and Green (2017) have applied the concept of contributory expertise to chronic patients’ knowledge and have demonstrated how, through their first-hand experiences of their illness, they acquire this expertise and become expert patients. This research has applied this framework to parents’ knowledge and experience of their child’s illness, and has demonstrated how through their experience of caring for and managing their child’s illness, they acquire contributory expertise and become expert parents. The next section looks at parents’ interactional and special interactional expertise.

7.2.2 Parents’ Interactional Expertise and Special Interactional Expertise

Being able to engage in the expert discourse of a specialist community is what Collins (2014) labels ‘interactional expertise’; “interactional expertise is acquired by engaging in the spoken discourse of an expert community to the point of fluency but without participating in the practical activities or deliberately contributing to those activities” (p68). The majority of parents interviewed demonstrated a good level of comprehension and familiarity with medical discourse related to their child’s disease and its management; the extracts below are examples of this:
“...if you try to remove the entire thing (tumour) you can damage the hypothalamus, you can damage the pituitary, you can, you can leave more damage than doing good, so there was, I suppose different thoughts was how much of the tumour should be removed and how it should be removed, whether it should be removed by craniotomy, whether it was possible to remove it transsphenoidally through his nose...” (Linda)

“...he was left right away with something called Posterior fossa syndrome, which happens when you operate in the cerebellum of the brain, erm in about 20% of all cases patients are left with a syndrome that causes mutism, erm, paralysis...”

(Hazel)

“...so, they did what they call a P53, I don’t know if you’ve heard of it, a P53 mutation, so they did a test on me to see if I have P53 mutation, so basically, we’ve all got P53, which breaks down cancer cells...” (Carol)

These accounts are evidence of parents possessing some degree of interactional expertise in relation to their child’s condition. Linda and Hazel had knowledge and were familiar with terminology related to their child’s site of disease, i.e. brain, and the medical procedures and syndromes attached to this, whilst Carol demonstrates to have knowledge about terminology related to the aetiology of her daughter’s tumour. Some parents were also found to possess ‘special interactional expertise’. According to Collins (2014), special interactional experts are; “people who acquire interactional expertise through occupying a strange role in which they immerse themselves in the discourse of a specialist community without fully participating in
that community’s expertise” (p116). These parents demonstrated an in-depth level of familiarity and comprehension with the medical discourse, which was notably at odds with the others. The anecdotal claims informing their narratives set them aside from the other interviewees, where they claimed to have expertise on a par with that of the medical professionals involved.

In the case of Hazel for example, this mother talks about interpreting and comprehending information related to her son, Nick’s, cancer and the benefits and side effects of the different treatments used to treat his particular type of tumour. Hazel weighs in on the proton vs photon debate and offers her opinion about proton therapy being the only tool which can treat Medulloblastomas;

“…there was no evidence that proton is better than photon in treating the cancer and that is still the case, it’s not better in treating cancer, but it is the better in the side effects…”

“…proton is the tool to fight that type of cancer that Nick has, chemo is only kind of a little, you know, safety net, if he’d only had chemo he wouldn’t be here today, erm, if he’d only had surgery he wouldn’t be here today, it’s the proton that fights this particular cancer…”

Hazel’s special interactional expertise is especially evident where she expresses her understanding about the thresholds and margins in place which regulate access to proton therapy, and questions these;
“Hazel: in fact what they (the NHS hospital) said is, ‘we think he’s over this threshold, but only just by .3 mm’, or you know, very, a very narrow margin, and, it’s difficult ‘cuz then you think, ok, you know, this figure that they have, so there was a figure, it’s 1.5 cm³ I think, of tumour left behind, and anything over that threshold would make you high risk,

Interviewer: Ok,

Hazel: but who came up with this threshold, it’s an arbitrary figure, and if you’re 1.7 or 1.8, who says that that is worse that 1.4 or 1.3, so a child with 1.3, you know, cubic centimetres left behind would be treated standard and a child with 1.7 would be treated as high risk, and the high risk protocol is really debilitating, it leaves kids with terrible, terrible disabilities ‘cuz of the radiation is so harsh on the brain”

Hazel recognises the protocols in place, but challenges this and explains that the high-risk protocol involving X-ray (photon) radiation can be extremely debilitating and will leave young brain tumour patients with severe disabilities, due to the high dose of radiation exposed to the brain. Prior to opting for PBT, Hazel was undecided about which course of treatment to proceed with for her son. She explains that the primary hospital in the UK were against the idea of PBT, on the basis that under the circumstances it would not make “much difference” than standard X-ray radiation treatment would. Protesting this view, Hazel explained that whilst this view might be correct, “it makes some difference”. Against the advice of Nick’s primary NHS doctors, Hazel decided that PBT is more adept at treating her son’s tumour. This decision was informed by her own research and the input from various professionals which she had sourced and consulted during the process.
From the onset of the interview, Hazel articulates her claim to expertise. Hazel suggests that she is an expert of her son’s tumour and anything related to it, and implies that other parents are also experts in their child’s condition. In the extract below, Hazel is offering advice to parents on what to do when their child is diagnosed with cancer;

“...if I hear about anyone, erm, being diagnosed, any child being diagnosed, the first thing I always tell them is, find a parent network, parents know so much, I mean, you know, we are, we know more than our oncologists do, because they need to know a lot about a lot of cancers and a lot of things and they have a lot of patients and clearly they are the experts, clearly, but as parents you become an expert in your child’s condition and everything related to that condition…”

Whilst Hazel is recognising the expertise of the medical professional, i.e. oncologist, she is suggesting that their knowledge is broad yet limited, in comparison to her own in-depth and specialised knowledge of her son and his condition.

Similar to Hazel, Peggy also demonstrates familiarity with expert medical discourse, which arguably goes beyond what would be deemed necessary for her to manage her son’s cancer. Peggy’s account is loaded with medical language, technical phrases and a high degree of comprehension of the medical discourse. It is noteworthy that during the transcription of this interview, I frequently had to look up the meaning of the different medical terminology she used. The extract below, although lengthy, demonstrates Peggy’s special interactional expertise. The excerpt is from a part of Peggy’s account where she is talking about her son, Ashley’s, PBT related side effects. Peggy states that Ashley is “sat right in the middle of side effect profile”, where some of the side effects of proton therapy have emerged sooner than expected. In order to ascertain the cause of some of these side effects, Peggy explains that there
was need for longitudinal MRA (Magnetic Resonance Angiogram) data. However, contrary to the proton centre’s recommendations, the UK cohort of doctors had failed to conduct an annual MRA scan. Here, she explains how herself and the consultant neurologist managed to work out together the result of a missing MRA;

“… when you review an MRI, it’s in slices, within that slices you have a pictorial idea of what the blood vessels are doing, when you’re incredibly specific, you can just about work out the results of what an MRA should be, it’s an incredibly long process, because what the consultant neurologist and myself did on the MRIs, we compared them, slice by slice, we looked at the MRA that we’d had done, very clearly noticed a compression of a blood vessel on the side where Ashley had had proton, so we knew it was there, we had nothing to compare it to with an MRA to try and find out when did it start, because we knew what it looked like on a MRA, we were able to keep, we had that on one screen, we had the MRA on one screen on that aspect of the brain, we had the MRIs on 2 other screen, we then compared slice by slice and were able to work out between his scan June 14, that aspect of the brain was absolutely fine, September 14 on the same slice you could see something developing, the next scan was another, by that time we were then on 6 month scans, so we then jumped to a 6 month scan to the same aspect of the brain, very much evident, so between June 14 and September 14 we think is when it started, we’ve managed to ascertain that by very very specifically reading MRI scans, because we didn’t have an MRA to compare it to…”

It is possible that the consultant neurologist was in fact talking Peggy through the scans. However, as the remainder of the extract suggests, Peggy was working as an equal to the consultant;
Interviewer: It’s great that you could have been involved in doing that,

Peggy: Erm, yeah, it, I think I was lucky, again lucky, horrible word, it was the first time I’d met them, and they were introduced to me as a person who comes well prepared, eek! Not always a good thing, but I came with my blue folder, I came with my information, I came with my videos of behaviour, erm, I came with a lot of evidence and I came with a lot parental knowledge and they accepted that, yes I came with medical knowledge as well, they were open to try my suggestions as opposed to a health professional service that I’d worked (not professionally, but in reference to her son) with for 4 years, where I literally knew nothing, whereas I’d gone to a new service where, actually, I have got some knowledge, and they were willing to use that knowledge, so, I think that was different, literally the consultant and I kicked the other bods out of the consultant room, well, they’d gone down to the play room with Ashley and we sat there, two stools, ‘ok, I’ve got this’, ‘have you got that one’, and did it together.”

Peggy’s comprehension of medical knowledge, i.e. interactional expertise, is illustrated where prior to this anecdote she explains to me what an MRA is, “Magnetic Resonance Angiogram, so you know you’ve got an Angiogram for your heart, to show the blood flow, there’s a version that does the skull, so you’ve got MRI, Magnetic Resonance Imaging, so that’s a picture, and MRA shows the blood flow”, and as illustrated in the extract above, explains to me how an MRI (Magnetic Resonance Imaging) scan is interpreted. In explaining this she also says that you have to be ‘incredibly specific’, insinuating her skill and ability, when reading the MRI scans in order to be able to predict the result of an MRA. In this case, Peggy and the consultant neurologist are aiming to predict what Ashley’s previous, but missing, MRA scan would have looked like, so that they can compare it to his latest MRA result. This is a task which would
normally be reserved for a trained medical expert. Peggy also adds credence to her position in this clinical encounter by suggesting that her parental knowledge and medical knowledge were recognised and accepted by the consultant. This allowed her a private seating with the consultant, who apparently dismissed the other medics in the room, where together they analysed the MRI scans, predicted the result of a non-existent MRA scan and estimated a time for when Ashley developed a compressed blood vessel in his brain; “we’ve managed to ascertain that by very very specifically reading MRI scans”. In this last statement, Peggy aligns herself with the medical experts.

Hazel and Peggy have immersed themselves within the discourse and knowledge of the medical experts to the extent that although not medically trained, they regard themselves as possessing expertise which is on a par with the medics and allows them to take part in tasks normally reserved for a trained professional. Both parents were demonstrated to have possession of in-depth knowledge, which was arguably beyond necessary to manage their child’s illness.

In this section the different types of specialist expertise, which parents were found to possess have been explored. Parents were found to possess contributory and interactional expertise, as well as special interactional expertise. The following sections looks at how parents acquire such expertise.

**7.3 Seeking and Acquiring Expertise**

Interacting with various medical professionals in the context of different appointments and medical settings may have equipped parents with a level of medical discourse comprehension.
However, as this section demonstrates, parents also engage with expert discourse largely via support groups. Parents were found to rely on information sought from support groups at different points during their child’s illness and for various reasons; online support groups played a key role.

In her interview, Louise mentions having joined an online group in an effort to gain more information about her son, Liam’s, Chordoma tumour. Earlier in the interview, when Louise was talking about the biopsy taken from Liam’s tumour, she stated:

“…they did a biopsy through his nose, …’cuz that was the safest, what we thought was the safest way, since then I’ve learnt that you shouldn’t biopsy Chordomas… through my, on, you know continuous learning about that, because if you start biopsying Chordomas, they’ve got a massive risk of spreading, erm, so anyway,…”

Later in the interview, I probe Louise and ask her to elaborate further about the statement she made, above, regarding the biopsy:

“Interviewer: so, you mentioned that, erm, now that you have information you realised that they shouldn’t have done the, erm, biopsy,

Louise: yeah, the biopsy through his nose, yeah,

Interviewer: Is that, erm, did you read up about it?
Louise: yeah, well now there’s, I’m on the, erm, Chordoma Facebook page, so it’s specifically for Chordoma people, who suffer from Chordoma tumours ‘cuz it’s so rare, so there’s that community now that I’m learning from, I’m, I’ve, in a way sometimes I’ve detached myself a lot from the cancer side of things, from my own choice, ‘cuz I thought that wasn’t doing me any good, but particularly I wanted to stay in touch with the Chordoma, because of the research around it, because it’s one of the tumours that is likely to reoccur as well, erm, unfortunately, but there’s no research in relation to proton and Chordoma...”

Motivations to seek and acquire expertise are discussed later in this chapter, but as Louise explains due to the fact that Liam’s tumour is rare and is likely to return she has attempted to gain as much information as possible. More to this, she also mentions that there is very limited research in relation to ‘proton and Chordoma’. Louise make it clear that her motivation to join the group is to learn about the tumour, where she states that she has detached herself from the cancer side of things. She has joined the Chordoma group specifically to learn about her son’s tumour, from people who have also been diagnosed and have experience with Chordomas. It appears that Louise is supplementing gaps in scientific research and expertise, in relation to proton therapy and Chordomas, with the experiential knowledge of other sufferers.

The value and importance of online groups are also iterated elsewhere in Louise’ interview. Louise was interviewed with her husband, Callum. Their son, Liam, had undergone PBT close to five years prior to the interview; at that point, the PBT Facebook group did not exist. Whilst recalling the point at which proton therapy was recommended to them and they were trying to reach a decision about this treatment, Callum states that the radiologist assigned to help and explain to them about PBT was “useless” and “knew nothing about proton”;

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“…he (Radiologist) knew very little about protons, which is actually a type of radiotherapy,… it actually was one of those meetings where you come out and thought, that was a bloody waste of time, you know, we’re worse of now ‘cuz we’d got that doubt that they don’t know what they’re talking about, you know, you go into these things thinking that they (doctors) know everything about everything…”

Recounting their frustration about the lack of information, Louise explains that she “desperately wanted to talk to other families on treatment (PBT)”. She explains that the doctors would not give her access to other families, due to confidentiality reasons, and the proton Facebook group did not exist either. This suggests that perhaps if the group had existed, they would have used it to source their information about PBT. In the above exchange, Louise and Callum suggest that they initially viewed the medical professional as the epitome of knowledge. Callum states, “…you go into these things thinking that they know everything about everything…”; ‘these things’ arguably being either the collective illness experience, or the consultation with the radiologist, and ‘they’ refers to the medical professionals. However, as they have progressed in their experience with Liam and his illness, they appear to have distanced themselves from this view and rely on other sources of expertise. Louise states that she is continuously learning about and relies on the Chordoma group to supplement her knowledge. In the statement above, Louise suggests that the knowledge she has acquired from this group has led her to think that the doctors’ decision to carry out a biopsy, through Liam’s nose, may have been incorrect and has inadvertently put him at risk.

Hazel also alludes to the use of online support groups as a valuable source of information in the management of her son’s illness. As demonstrated in section 7.2.2, Hazel’s advice to parents, who are new to the experience and have only recently received a diagnosis for their child, is for them to reach out to their community of fellow parents. Parents, in her view, are
experts of their child’s condition and anything and everything related to it. Hazel speaks of having accessed a global community of parents in a similar situation to herself, via a Facebook group she has joined, proclaiming;

“...I wish I’d known about it (the proton group) as soon as Nick was diagnosed, because the, even just, putting you straight and telling you to, you know, stop considering a certain thing because it’s clearly rubbish for your condition or whatever, sometimes you need a reality check, you will get it there, there’s over 1000 (members) in our network globally, that’s the one thing, as soon as something happens with Nick, that’s the place I go to first....”

In this statement, Hazel is suggesting that rather than asking a medical professional for help and input, she relies on and prioritises the views of other parents in order to discern whether ‘a certain thing’ is suitable or not for Nick’s condition. If and when anything happens with her son, instead of seeking professional input, Hazel claims to first and foremost turn to her global community of parents. This affirms her view that parents are experts of their child’s condition and have in-depth knowledge related to it, whilst doctors although ‘clearly the expert’ know a lot about different cancers, yet their knowledge limited.

There is evidence to suggest that Hazel and Louise and Callum are not alone in holding this view about other parents’, and patients’, knowledge. Whilst these parents relied on the online parent communities for information related to their child’s disease and treatment, some parents sought a different type of parent expertise. This type of knowledge was different to the expertise which doctors and medical personnel can provide, for it is based on the lived experiences of the illness.
In the case below, Rochelle clusters together the technical, scientific and statistical data made available, to herself and her husband, in the information sheets and protocol reports and distinguished this form of knowledge from another important type of knowledge, which is equally important to her, as a mother of a paediatric oncology patient. The emotional and familial experiences and stories are valued by Rochelle as an important form of knowledge, which the professionals are unable to provide for her;

“...we were only given an information sheet about Rhabdomasarcoma, erm, we wanted a lot of detail on, we did get a report about the protocol that Katie was on, but all very technical, which my husband really liked the technical report, for him it really suits him to get that, but I quite like more of the kinds of emotional, erm, other families’ experiences, erm, how to make it easier for your child, and you get play specialists and things who do help you, who are very very good, but I’d probably have liked more access to them, ‘cuz you can’t underestimate, even a 3 year old child, you know, it has a huge impact however old you are and you can’t forget about them and their feelings, so I like more of the touchy feely stuff, but my husband likes all the kind of technical stuff...he likes statistics and science and so on, which I, you know, I don’t mind hearing, but, I prefer,...I like a story, like a case, I like a story about something and it’s good to hear stories, positive stories, negative stories, just so you, you know, you know what you’re dealing with either way...”

Similar to Rochelle, who seeks ‘stories’, Agatha speaks of the need to access ‘real life stories’. Agatha is a trained GP in her native country, although she does not practice medicine in the UK. She is well versed and adept at understanding the medical information related to her son’s
condition, yet she talks about her search for a different kind of knowledge which is important for her to be able to know how to manage his illness;

“…to be honest I am a medical person myself, what explained to me I read myself, what I want to hear always from the doctors is like real life stories from, well they would say to me, ‘right, we had this person and he had this sort of side effects, but we had this person and he had, you know, this side effects and this outcome’, that’s not what I want and what all normal people want to hear, not what everybody can read on internet or in brochures, ‘cuz I can read it myself, I’ve read 100 times what they say to me, about the 80% not coming back tumour, 20% coming back, you know, 50% hearing loss, 5% this side, it’s all statistics, I don’t want to hear that statistics, I want real life stories because, you know, statistics is so far away from reality than statistics, until you are dealing within your family you want to hear life stories, but of course, medical people are not allowed to tell you these life stories, because of the law (referring to patient confidentiality),… they will answer you that statistics which they read from the internet or from the books, you know, and what? It doesn’t put any peace in my mind…”

Agatha’s son, Jacob, has a rare type of tumour, and whilst she has managed to source some information about this tumour and its response to proton therapy, she speaks of her frustration in not having access and insight into actual cases concerning paediatric patients and their response to this treatment. Echoing Rochelle’s complaint about information sheets and medical reports, Agatha is also suggesting that there is only so much she can learn from what she has read on the internet and brochures. The type of textbook expertise that the doctors are offering to these mothers, is different and ‘far away from the reality’ of the lived experiences of the
illness. The analysis of information leaflets presented in Chapter Five, noted the absence of the patient and a biographical account of illness and treatment. For example, whilst the information leaflets mentioned that there may be side effects as a result of proton treatment, there was no mention of what these side effects may be. The content of the information leaflets was biased towards a biomedical model of the illness, where the capabilities of the technology were at the forefront of discussion. Agatha and Rochelle’s accounts highlight the importance of having access to the lived experiences of illness, whilst also suggesting that there is a type of expertise, important for managing their child’s experience of cancer, which can only be accessed and acquired from other parents and families who have undergone a similar experience to them.

Support groups have played an important role in filling this void of knowledge, where Rochelle and Agatha have both sought information from online forums and parent-run online support groups in order to access this type of ‘lived’ expertise. Rochelle, for example, relied on Facebook support groups for parents of children with cancer, as well as tumour specific groups. These online support groups play an important role in parents’ acquisition of expertise. In section 7.2.1 it was shown that a specialist nurse aided Rosalin in developing contributory expertise about her son’s condition and the use of medication for his underactive thyroid, a side effect of PBT. However, Rosalin also mentions relying on the input from two other parents. Rosalin mentions that she has a friend who she met on a hospital ward, and often speaks to her and says, “hey, this is what Mason’s got”. She is also in contact with someone she met via a Facebook group, whose son has the same condition as Mason and requires the use of similar medications, i.e. Thyroxine and Hydrocortisone, to manage symptoms of his underactive thyroid. Rosalin is in contact with these parents and seeks their advice on how to manage Mason’s symptoms and medication dosages. Mason is also Adrenal deficient and relies on the steroid hormone, Cortisol. Rosalin mentions that as well as relying on and seeing the local
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contact at the hospital quite regularly, she also relies on the internet for information and has joined Facebook groups, ‘UK and worldwide ‘Cranio’ Facebook groups’, to learn about and manage his Adrenal deficiency.

This section has demonstrated that support groups and other parents play a key role in parents acquisition of expertise, where the majority of parents spoke of having joined and accessed a variety of support groups for information. In his research involving prostate cancer patients, Green (2017) found that men’s participation within self-help groups played a key role in their acquisition of expertise; a combination of clinical encounters as well as encounters with medical professionals and other patients at support group meetings was key to these men’s acquisition of expertise. In this research, parents spoke of largely relying on online support groups. The use of disease specific, treatment specific as well as designated online parent communities were reported by parents. The growth in the use of web-based health related information is nothing new, where the majority of healthcare consumers are able to search their conditions and access vast amounts of information (Nettleton 2004), something which has supported the creation of expert patients (Henwood et al. 2003). In the case of this study however, the heavy reliance on online groups may be due to the fact that proton beam therapy is novel and the use of it in comparison to conventional therapies is limited and sporadic in the UK; therefore, virtual rather than physical support communities have been formed. The same principle may be applied to the rare nature of the tumours, for which PBT is employed to treat. The infrequent post-PBT appointments and limited access to medical professionals, may also have led to the heavy reliance of these parents on support groups and online communities.

The importance of support groups and access to fellow parents’ expertise has been acknowledged. Participants suggested that parents are able to offer a level of expertise related
to a certain condition, which doctors are unable to provide. Additionally, it was also suggested that in the management of their child’s disease, a specific type of knowledge is required, which only fellow parents possess and can share. Parents were found to want access to the lived experiences and realities of the illness, which the medical professionals were unable to offer.

It is of course important to acknowledge the fact that the large majority of participants were recruited via an online support group, and this may have distorted the findings of this section. Parents may have joined the online group with the intention of sourcing and sharing knowledge and experiences with other members of the community, and these behaviours were recounted in their interviews. However, this section has drawn attention to the value and importance of other patients’ and carer’s knowledge, and the reasons for which these parents sought their expertise.

### 7.4 Sharing Expertise

In the section above, the importance and value of other parents’ knowledge and expertise was noted. In this section, the way parents share their expertise with others is discussed.

Most of the parents in this research initially spoke of having no awareness or understanding of proton therapy, whilst some explained that they had heard of the treatment via the media and through their own research. All of these parents talked me through their quest to source information in order to understand the mechanics and risks of treatment, once it had been recommended for their child. Parents had sourced information from medical professionals, as well as resources primarily accessed via the internet. Talking me through their narratives the majority of interviewees reached a turning a point, where their role changed from a parent
seeking specialist PBT knowledge to someone who is able, and willing, to share their expertise with others. Jennifer’s account neatly summarises this point;

“...I had no comprehension of the knock-on effects (referring to PBT), so it was a steep learning curve to then go away and do a bit of intimate research and figure out what it was all about. Got to a point, you know, where I was capable of explaining it to somebody and capable of explaining what happens afterwards to somebody as well…”

Various platforms were reportedly used by parents to share this acquired specialist knowledge about proton therapy. Parents spoke of having participated in numerous workshops hosted by their primary NHS hospital and charities, as well as participating and contributing to various online support groups aimed at paediatric oncology families focused on raising awareness about proton therapy and the PBT experience. Peggy is strongly active on this front and the following extract is an example of how she explains PBT to parents whose child is due to undergo treatment. Whilst Peggy is capable of employing a technical dialogue to describe proton therapy (demonstrated in her interview and evident in the sub-section above), she makes use of an everyday metaphor in order to pitch this to her audience. By adopting this approach, Peggy is facilitating novice proton-parents’ acquisition of proton therapy related expertise;

“...that’s how I describe it to the families that I’ve spoken to since, who didn’t also know anything about proton, erm, a bit like also, sort of like a shower head as well, you know, where you’ve got, when you turn the shower and it gets much more directed as opposed to the wider shower head where it just hammers everything else around it…”
As well as sharing their specialist knowledge of the proton beam technology, parents were also keen to share information about the collective experience of treatment; how to prepare for the journey abroad, what to expect from treatment and the proton centre, as well as the overall experience of living abroad and managing their family whilst their child is undergoing treatment are the kinds of information that parents shared with others. In section 7.3, it was found that in the management of their child’s illness and proton treatment parents seek and value a unique type of expertise, which the medical professional is unable to offer. Parents seek knowledge about the reality and lived experience of the illness. A number of parents described seeking and later sharing information related to PBT and the proton experience. This is arguably a unique form of experiential knowledge, that only a fellow proton parent possesses.

Explaining how she prepared for her son’s proton treatment and her family’s move abroad, Carly describes the overall experience as daunting and recalls feeling at a loss at the very beginning. She explains that she was a member of the proton Facebook group and used this platform to ask numerous questions about accommodation, the treatment centre, how to prepare for the trip and what to expect from treatment. The tone of her interview changes however, where she later goes onto describe her own involvement and contribution to the very same Facebook group from which she had initially sourced information from;

“I keep in touch on that proton group, people asking questions when going out, and there’s one family that’s out there at the minute, she’d contacted me with a few questions and I said to her, honestly, you’re going to have the best time ever,...” (Carly)

Carly, and other parents alike, mention that it feels good to be able to answer questions and guide other parents. The value and importance of this experiential knowledge, possessed and
shared by Carly and other parents alike, is demonstrated in the case of Graham and Heather. Their son, Charlie, was part of the first round of paediatric patients to be sent abroad for proton therapy. Both parents explain that other than the information given to them by their medical team, which was very limited, there was no other sources of information available to them. They had no access to detailed information about the treatment and about how the proton centres in America and their overall experience would be; for example, they did not know what treatment entailed, how Charlie would respond to treatment, the type of accommodation they would be living in and whether it would be appropriate to take their other children with them. Not having this information meant that they were unable to make an informed decision when it came to deciding on how to manage and involve the family in this experience. Heather and Charlie explain that if they had known what the experience entailed, then they would have travelled together and not split the family, something which they explain affected both themselves and their children. At the closing of their interview when I ask whether, in retrospect, they would have approached matters differently, their response is as follows;

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“Graham: I think if we’d had more information, we could have involved the rest of the children much more, because they definitely, they missed their mum dramatically, it’s not the same with only daddy, and they never really understood, like Charlie’s brother was convinced, erm, but we didn’t know enough to be able to reassure them,….

Heather:… yeah, I’d just get more information for you to make that informed decision, yeah, they (the doctors) can guide you medically, but you have to make the best decision for your family, and that’s what I would say to people going, …”
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The point raised by Heather iterates the point, which was made previously in this chapter, about parents seeking and valuing the lived and experienced expertise of other parents and their families. According to Graham and Heather, the knowledge shared by the medical team was not sufficient enough to inform and guide them and their family through the experience of their son, Charlie’s, proton treatment.

Various platforms were used by parents to share their expertise about proton therapy and the PBT experience, with other parents. Some parents were motivated to share this expertise in order to raise awareness and to promote best practice. The majority of online support groups, i.e. Facebook groups, are closed groups; this means that you must make a request to join and be accepted by the administrative group in order to become a member. I myself had to request permission to join the online group from which I wanted to recruit parents from for my research. In one instance I had requested to join a certain group, but was not granted access. Peggy explains that this regulatory process and guarded approach is adopted so that the content of information disseminated in the groups can be regulated;

“Peggy: ...people basically just trying to fob us off and say Cannabis cures everything, erm, so yes you do have to be aware of what’s out there, erm, when the Ashya King thing kicked off and proton had a little bit of lime light time I think a lot of information that went out about proton was incorrect, I think that was giving people false hope.

Interviewer: Yeah,
Peggy: It’s hard, it’s really really tricky, I’m hoping with increased Cancer Research UK for paediatric cancer, so I’ve worked with Children with Cancer and Leukaemia Group as well,”

In the above extract, Peggy is suggesting that she is able to distinguish whether certain information about PBT is correct or not. Encouraged by the specialist knowledge she has acquired from her son’s experience with PBT, Peggy has picked up the task of raising awareness about childhood cancer as well as promoting correct information about proton therapy. Similar to Peggy, the acquisition of specialist knowledge by Rochelle has encouraged her and her husband to establish a charity focused on promoting and sharing best practice. Rochelle explains that she wants to share knowledge which she has learnt through her experience involving the UK and US medical settings;

“...we’ve actually decided to, we’re trying to, we’re setting up, we’ve registered a charity which is ‘gunna look at, erm, it’s ‘gunna look at kind of how to share the sort of best practices that we learnt in the US and the UK, also focusing on, a lot on clinical research into Rhabdomasarcoma, so we’re just starting, we’ve got it all sorted, we’ve got it registered, we set it up about 2-3 months ago, but that was kinda inspired by the fact that we went to the US, erm, and we were in a position to be able to make these observations about all of the treatments, erm, and then there’s also little things like you know, access to kind of toys and activities and that kinds of thing in a hospital...”

By sharing their expertise with others, parents aim to inform other affected families about proton treatment and experiences of treatment; the latter being an important type of expertise which the medical cohort does not possess. Parents also shared their acquired expertises in order to raise awareness and promote best practice. Various platforms, such as charity-run
workshops and online support groups are reportedly used by these parents, where the latter plays a key role in providing a platform for parents to share their expertise.

7.5 Motivations to Become Expert

This section will explore some of factors which are thought to have influenced parents’ acquisition of expertise; this research has identified a number of motivations and facilitating factors.

Section 7.2 explored the types of specialist expertise that parents in this study were found to possess. Parents were found to have acquired different degrees of contributory, interactional and special interactional expertise. One of the mothers, Kelly, whose account was used as an example to illustrate parents’ contributory expertise, suggested that having acquired her skills and knowledge meant that she did not have to rely on the medical professionals for help. For example, learning how to flush her daughter’s IV line and change her dressings, saved her from having to make a trip to the hospital. Acquisition of this contributory expertise enabled her to take charge and better manage her daughter’s illness, and served to be more practical. Another mother who was found to possess a degree of specialist expertise was Carly. In her account, Carly suggested that she is able to comprehend information related to her son’s illness and to interpret his medical scans and results;

“...you read about the, ‘yeah, the proton is better than radiotherapy’, and when you’ve been a part of something like this for so many years, you tend to understand, you know, I read a lot, so yeah...”
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“...I’ve seen the scan and can sort of read the scan enough now...”

In the latter quote, where Carly speaks of her ability to read Shane’s scan, this was mentioned in the context of her wanting to validate and corroborate the oncologist’s interpretation of the post-PBT scan. Evident in her account is an implicit need to exert a level of control in the management of Shane’s illness. This quest to exert control is further apparent in the extract below;

“...I’m just one of those parents that’s used to writing everything down, every week when we’d go for chemo and they’d check his bloods, I wanted to write it down so I knew, that’s just me, some parents don’t, but I needed to know, I needed to feel like I knew as much as the doctors, because I can’t do anything, you know, he’s basically in their hands, but if I could understand a little bit more, so you now, I do trust our oncologist and I know she’ll follow through, it’s things like the blood tests I’ll make sure he’s always having blood tests even though he maybe doesn’t need them as often as they’re doing them,...There was a little boy that was exactly the same as Shane and if I would ask his mum what his, you know, haemoglobin was that day, she wouldn’t know, she just, but she wasn’t, not that she wasn’t bothered about it, but that obviously wasn’t important to her to find that information, but I just felt I needed to know everything, everything they were writing down I needed to know...”

Carly knows that there is a limit to the work she can do in the context of Shane’s illness; the doctors are in the position to practice medicine and ‘he’s basically in their (doctors) hands’. Whilst she proclaims her trust in the oncologist, she also states that she ‘needed to feel like she knew as much as the doctors’. By trying to learn and know as much as the doctors, Carly is arguably trying to exert a level of control. She exercises control over Shane’s situation by
keeping track of and checking his tests results, knowing what is normal and by requesting further tests where possible. Carly is not alone in this quest to claim control, where other parents, such as Peggy and Claire for example, also speak of asking ‘for numbers’, keeping a log of all information and requesting further tests and scans for their children.

In Peggy’s case, having this knowledge and expertise meant that she was in a position to challenge and disagree with her son’s medical team and gently steer his medical pathway. Peggy is in praise of both the NHS team and proton centre medical staff involved in the care of her son. However, in some parts of her interview she vocalises her criticism towards some of the medical practitioners involved. In the sub-section 7.2, Peggy suggested that she has parental knowledge and medical knowledge, and whilst in the instance mentioned above she suggests that this knowledge was acknowledged and welcomed by the team of medics, in some instances, this led to disagreements;

“...I think it is where the disagreements, (referring to her disagreement over the frequency of Ashley’s post-proton follow-up scans), with the consultant team have come from as well, when I as a parent have been proactive, they’re like ‘you know that’s our job’, and I’m like ‘do your job properly then love’, you know, then I wouldn’t need to intervene...”

Peggy explains that she has created a medical file for her son, Ashley, and will take this with her to different appointments;

“... I do have documentation back from that time, but not as in depth as I have now, erm, I quite often go from A to B with Ashley’s medical file on me, erm, that I’ve compiled, erm, and especially when we get new people involved, erm, I basically give them the blue file and say happy reading...”
Peggy’s motivation to keep her own record of Ashley’s medical file are three-fold. First, it helps her keep track of the vast volume of information provided to her by the doctors. Second, she aims to ensure that Ashley’s medical information is shared with more ease and speed than it would take the different medical teams involved to share. Her third and final motivation is so that she can keep the wide group of health-care practitioners involved in Ashley’s care informed about his case; “from Ashley’s wider group of health follow up, I’m greeted with ‘what the fuck’s that?’, I don’t, I very often don’t even mention his diagnosis, because that again goes onto ‘what the fuck’s that?’, I will say proton beam radiation if prompted”. This suggests that in some instances she encounters some professionals, who she does not think have adequate information about Ashley’s tumour and the treatment, i.e. PBT, he has undergone. By acquiring and sharing the expertise she is demonstrated to possess, she is able to exert a level of control in the management of her son’s illness. Peggy suggests that her knowledge allows her to keep doctors in check and also plug the gap in some of the other professionals’ knowledge. In this instance, there is something unique about the case of PBT, where Peggy is suggesting that she possesses expertise about the treatment, which the wider cohort of medical experts may not necessarily possess. There’s a nuance of shared view with Hazel, who explicitly states her view that parents are the experts of their child’s condition and of everything and anything related to it. These findings corroborate existing research which suggest that the impetus for control of the situation drives some parents to become experts of their child’s disease and matters related (Smith et al. 2012 and Clarke & Fletcher 2003). Parents will learn about the complexities of the disease and treatment and learn to master complex care and treatment skills, through experience (Smith et al. 2012 and Clarke & Fletcher 2003). In these instances, the fact that proton therapy is a new form of treatment is also motivation for these parents to acquire knowledge and expertise about their child’s condition and treatment.
So far, it has been demonstrated that parents acquired expertise about aspects of their child’s condition in order to reclaim lost power and exert control over their child’s healthcare pathway. In some instances, they seek to acquire expertise in order to fill the void in other professionals’ knowledge. As demonstrated in Peggy’s account, she sometimes encounters professionals who knew nothing about PBT and therefore by sharing her accumulation of knowledge, logged in her folder, she aims to plug this gap. However, the acquisition of expertise appears to be also driven by a moral imperative indicative of good parenting. In the account above, Carly refers to herself as ‘just one of those parents’ when speaking of the way she keeps track of information related to Shane’s illness, and alludes to another parent, in a similar position to herself, who does not know her son’s haemoglobin count. In making this comment, Carly makes a distinction between types of parents, and she is not alone in making this comparison; the extracts below are a testament to this.

“...I do think that as a parent you have to be on the ball, you have to know what medicines they’re taking and you have to know what you’re doing, where you are in treatment and all of that, so I suppose I find that kind of stuff easier, but I suppose for all parents it doesn’t come easy to some people maybe...” (Kelly)

“...I think we (herself and her husband) are pretty proactive parents, I think that also, frankly, we fought even while we were in J (proton centre), some people must really struggle, because, not to say we are much more capable of other people, but, we know, you know, we know how to drive, we can communicate, you know, English and you know, there must be people for whom this is really a tough thing to do, you know, I think you have to have your wits about you, it’s not a simple thing...” (Linda)
In these accounts there is an implicit doctrine of what constitutes the duty of a parent. Emphasising their duty to take responsibility and be proactive in the care of their child can be understood as a way for these parents protecting the threat to their status and duty as parents. The social construction of childhood depicts children as vulnerable and in need of protection, where it is the duty of parents to conform to traditional ideologies of care and devote themselves selflessly to the welfare of their child (McKeever and Miller 2004). Such cultural connotations are especially magnified within the experiences of seriously ill and/or disabled children, where this dominant discourse pervades notions of what is considered to be a ‘good’ parent (Dixon-Woods et al. 2005, Lupton and Fenwick 2001). Failure to become expert and maintain or achieve optimal health can therefore be viewed as failure to fulfil one’s obligation as a good citizen (Peterson 2006) and fulfil one’s moral duty (Rimke 2000). Therefore, emphasising the importance of being in control and possessing expertise concerning their child can be understood as a way of parents reclaiming and protecting their moral status as a parent, which comes under threat when a child is diagnosed with cancer and, in the cases involving these parents, is treated with this new type of radiation therapy, i.e. PBT.

7.6 Factors Facilitating the Acquisition of Expertise

In the closing segments of the above section Linda and Kelly both suggested that perhaps it is not easy for every parent to have a full grasp of matters concerning their child’s condition. Drawing on this idea, this sub-section will briefly look at the factors which are thought to facilitate parents’ acquisition of expertise related to their child’s illness. Recalling the lead-up to their son’s appointment for brain surgery Michelle describes Samuel, her husband, as feeling unsure about the proposed treatment protocol and suggesting to her that
they reconsider and look for an alternative option. Michelle explains that Samuel’s hesitation
was due to him not fully comprehending the information and situation which their son was in;

“…he’s (her husband, Samuel) never been ill, never been in a hospital
environment, doesn’t understand what they’re talking about, doesn’t understand
the terminology; it’s all, it’s all, I dunno, like a foreign language to him, it’s all like
a foreign language to him, but I know what they’re talking about, I know the
abbreviations they use, I know a lot of what they’re saying and I know how serious
this shit that he’s (her son) just been through is…”

Michelle is a research biologist by trade and her husband is a lawyer. There is no doubt that
the specialist knowledge that Michelle has developed within the realm of her profession has
helped her approach and manage her son’s illness, differently to her husband.

“…I think if Samuel (Michelle’s husband) had been dealing with it instead of me,
I don’t think he would have dealt with it like I’ve dealt with it, ‘cuz he has no
experience and no knowledge of the medical world what so ever, it is all Greek to
him and he was quite sort of ‘oh my god what does this mean, oh my god what
does that mean, that sounds terrifying, can we let him do that, is that’, erm,
whereas I was a lot more, ‘no that’s fine we need to let him do it’, so perhaps my
knowledge and my personal experiences have made my journey and my
experience that little bit different to everybody else’s…”

The specialist expertise that Michelle has acquired through her trade and working in a hospital
environment have helped her further pursue and acquire new expertise in relation to her son’s
illness. It is suggested that patients will utilise their occupational skills in their role as expert
patient (Wilson et al. 2007). Furthermore, Michelle also explains to me that she has been ill

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throughout her life and refers to her personal experiences involving illness when explaining why and how she is better adept at managing her son’s illness, compared to her husband. Michelle refers to her expertise as a biologist and experience as a former patient, i.e. contributory expertise, which have enabled her to better comprehend and acquire a new expertise concerning her son’s illness. Similar to Michelle, Jennifer also refers to the specialist expertise she has acquired through her trade, as a lab technician, which she applies and utilises in the management of her son’s illness;

“Jennifer: …I don’t find the medical side of things that, bad not really, just because I worked 18 years with,

Interviewer: You’re familiar with it,

Jennifer: Yeah, I’m familiar with it, so I don’t have an in depth knowledge obviously, but when I read a report, when they send you the reports, ‘I was very happy to meet Wilson and his parents in clinic today’, and that first paragraph is in English and understandable and then the rest of it isn’t, because it’s been written to your GP in doctor lingo, I can, my husband says to me, ‘well I don’t understand what this means’ and I can figure out what they’re talking about and I’ll go away and look up what that word means, but most of the time I can figure out what it means, but I can certainly understand how somebody who has not ever been in any kind of medical situation other than their own medical care will probably just look at one of those reports and think ‘I haven’t got a clue’...”
Jennifer’s familiarity with the medical terminology, knowledge she has acquired via her profession, helps her understand the medical dialogue of Wilson’s report; an ability her husband, who is an engineer, does not have.

The specialist expertise which the likes of Jennifer and Michelle possess by virtue of their professional work is transferable and applicable to the context of their child’s illness. Parents refer to their expertise when acquiring new types of specialist expertise for managing their child’s illness.

7.7 Summary

This chapter set out to explore the knowledge and work carried out by the parents of children treated with proton therapy, and to examine this through the lens of expertise.

The notion of expert carer or expert patient has proven problematic for some scholars, where Prior (2003) for example has suggested that their expertise is limited to an individual case only and does not reflect the broader facets of the illness; their knowledge is ‘partial and restricted’ (p48). Prior calls for clarification of the use of the term ‘expert’. Collins’ framework of expertise proved useful for understanding and conceptualising parental expertise. Applying Collins (2014) framework of expertise, parents interviewed for this study were found to have a range of expertise in relation to their child’s condition. Parents were found to possess contributory, interactional and special interactional expertise. Whilst Collins’ framework of expertise has previously been applied to patients’ first-hand experiences of their illness, in order to demonstrate their expertise as a patient (Green 2017), this research applied the
framework to parents’ knowledge and experiences involving their child’s illness. To this end, parents were found to be expert parents in relation to their child’s condition.

Parents develop niche pockets of expertise through their experiences of caring for their child; parents acquired a range of medical knowledge related to their child’s condition and grew to learn about their child’s body and response to treatments. The role of parent’s unique knowledge of their child and the contribution of trained professionals in the acquisition of contributory expertise were noted. Some of the parents were found to be in possession of a range of expertises, which went beyond what is necessary to manage their child’s condition; these parents were found to be in possession of interactional and special interactional expertise. Contrary to the passive notion of parents depicted in the documented discourse of proton paediatric families, these parents were found to be in procession of different types of expertise which they utilise in the management of their child’s illness.

Having established the different types of expertise possessed by these parents the value of this expertise to the wider community of parents was demonstrated. Parents were found to rely on other parents’ niche areas of expertise, i.e. disease specific, or treatment specific. In some instances, parents relied on this expertise in order to supplement gaps in medical knowledge and research related to the effects of proton treatment, as well as the rare type of tumour their child had been diagnosed with; this behavior in particular stood out to me, for it is synonymous with the role and task assigned to the professionals about plugging gaps in knowledge surrounding PBT. In the introductory chapter of this thesis, Crellin (2018) was quoted as calling out for gaps in the evidence base surrounding PBT and related uncertainties to be addressed; his audience are the professionals involved. Parents also drew from fellow parents’ expertise in order to form judgments about medical professional’s practices.
Parents also distinguished the need for a unique type of expertise, which the medical profession is unable to offer them. Some parents explained that they seek the ‘lived’ and ‘real experiences’ of their fellow oncology families, in order to be able to respond to and manage their own and their child’s experiences of illness and the proton experience. Parents explained that there is a limit to the type of information they can access via their healthcare professionals, the internet and information leaflets, which does not reflect their broader needs. Indeed, analysis of the information documents for example revealed that a biomedical model of illness, viewed through the lens of the technology’s capabilities was prioritised over the biographical patient experience. This research has demonstrated the wider breadth of research that parents seek in the management of their child’s illness. This parental experiential knowledge was also especially valued given the context of proton therapy, i.e. the need to travel to treatment centres abroad. Parents explained that the doctors can guide them medically, but cannot guide and prepare them for the actual experience of treatment, especially in aspects involving the wider family.

Online support groups were found to play an important role, where the majority of parents spoke of having sought and acquired specialist knowledge via online communities. It was noted however, that the context of PBT may have a role in these parents’ wide surge towards online groups. At the time at which this research was conducted, access to PBT was restricted and only available via proton centres abroad. To this end, the number of proton treated patients was limited, and sporadic across the UK. This may have led to the creation and use of online, rather than physical support groups. Additionally, parents’ numerous references and reliance on online groups may in fact be partly due to the fact that they were recruited from an online group and are therefore oriented towards participating and facilitating these support groups. Perhaps parents' possession of interactional and special interactional expertise can be partially attributed
to their participation in these support networks. It was demonstrated that the role of parents changes from someone seeking parental expertise, to someone who is willing and able to share their expertise with others.

The attainment of expertise was found to be partly driven by the impetus for control and to reclaim the loss of power, which parents experience when their child is diagnosed with a serious illness. Aware of the limits of their role, parents task themselves with learning as much as they can about their child’s condition and everything related to it in order to exert control over the situation, where possible. Emphasising their duty to take responsibility and be proactive and knowledgeable in the care of their child was also understood as a way for parents to protect the threat to their moral status and duty as parents. Cultural connotations attached to the construction of childhood and parenthood pervade notions of what is considered to be a ‘good’ parent, especially in the context of a child’s illness. Failure to become expert and maintain or achieve optimal health can therefore be viewed as failure to fulfil one’s obligation and moral duty. Parents’ acquisition of expertise was also found to be facilitated by their occupational background and professional training, as well as their past experiences as a patient.

This chapter has demonstrated that contrary to the proton documents’ depiction of parents as passive actors in the experiences of their child’s illness, they are in fact in procession of a range of expertises, some of which are quite distinctive to the proton therapy situation, and which enables them to navigate and take on a more active role in the management of their child’s illness and proton experience.
Chapter 8: Post-treatment Accounts; Uncertain Futures and Recovered Pasts

8.1 Introduction

This chapter is focused on parents’ accounts involving post-treatment experiences. The chapter highlights a range of uncertainties which parents speak of in relation to their child’s future, and also looks at how they formulate views of their child’s recovery. Additionally, aspects of parents’ own recovery are explored.

As demonstrated previously, the notion of recovery is complex and multifaceted, where fitting within a single framework of recovery is problematic, and unachievable. Recovery from illness typically refers to a return to normal and re-establishing of the pre-illness status quo (Parson et al. 2008), and a transitioning back to a healthy status (Radley and Taylor 2003). Whilst this notion of recovery may be achievable for some, for others, treatment related side effects and other health complications arising from illness means that achieving this sense of recovery is unlikely (Bell and Kazanjian 2011). Recovery is also conceptualised based on personal values and goals and the ability to re-establish continuity of selves, roles and relationships in face of change (Grant et al. 2009, Godfrey and Townsend 2008). The ability to return to normal or at least maintain some level of normality is considered an important element of recovery (Foster and Fenlon 2011), and where health complications make engagement with a prior-self impossible, a changed or new normal is accepted (Balmer et al. 2015).
In their interviews, parents rarely make direct use of the term ‘recovery’. In examining their post-treatment accounts, whilst looking at references made concerning the child’s recovery of health and well-being, this research will also look at recovery to mean a return to normal and/or preservations of normality; this view of recovery is formulated based on the literature review. In parallel to talking about their child’s ongoing health issues and physical disabilities, which bar them from any meaningful sense of recovery from illness, parents talk about their child’s ability to resume some of the routines and hobbies, which constituted the norm prior to the acute phase of illness. The child’s pre-diagnosis life is used as a yardstick against which these aspects of recovery are measured. Parents also speak about aspects of recovery in relation to their own lives and experiences, where they talk about their ‘new normal’, as well as working on recovering their parental identity and role towards their other children; which was hindered due to the disruption brought about as a result of the child’s illness.

This chapter draws attention to the fact that recovery is complex and multifaceted and means different things to different people. It also highlights that recovery, in the context of childhood illnesses, is not only limited to the patient, but that parents, caregivers and families undergo a process of recovery following the child’s completion of treatment. In some instances, the context of PBT, i.e. the need to travel for example, shaped these accounts of recovery.

Parents also spoke about a range of uncertainties pertaining to their child’s life. Three areas of uncertainty, related to surveillance, relapse and proton treatment were observed in these parents’ accounts.

This chapter is broadly divided into two parts. The first half of this chapter, comprised of section 8.2 and 8.3, is focused on the long-term uncertainties and on-going health issues.
Contrary to the expectation that treatment will be followed by a return to health, parents speak of a range of ongoing health issues and long-term uncertainties, which have shaped their expectations of their child’s future. Sections 8.4 comprises the second half of this chapter and is focused on meanings of recovery. Recovery is regarded as the ability to return to normal, or at least maintain some level of normalcy. A tangent to recovery exists, which is shaped by the ability to retrieve and maintain pre-cancer identities, roles and relations. With a focus on parents’ accounts of recovery in relation to their child, and themselves, recovery from childhood illnesses is conceptualised a joint venture between parent(s) and child.

8.2 Post-treatment Uncertainties

The focus of this chapter is on parents’ accounts following their child’s proton treatment. Parents’ reports of their child, post-treatment, are primarily set in the context of continued illness and health related concerns and ongoing uncertainties; the focus of this section is on the latter. Three areas of uncertainty were observed in parents’ accounts. The first area of uncertainty arises as a result of routine screening and surveillance. The second area of uncertainty pertains to an uncertain future marred by the fear of relapse. The third and final area of uncertainty arises as a result of uncertainty surrounding proton treatment and its unknown implications, due to the lack of long-term evidence. These uncertainties largely pertain to the future and the unfolding of the child’s illness and disease.

8.2.1 Uncertain Futures: Surveillance

Although many parents talk about marked signs of their child’s tumour dying and responding to treatment, absent in their accounts is any statement nor a clear turning point sign-posting the
end of their child’s illness. Every interviewee, bar one, talked about post-treatment scans and tests which showed signs of the tumour dying or being in a desired stable condition. However, these comments were then followed up by a discussion of further tests and observations, which loom within their child’s future, and uncertainties about how the child’s future may unfold. Parents spoke of routine tests required to monitor the tumour’s behaviour and a long-term medical plan in place to keep their child’s health in check. The extract below, from my interview with Claire, is a prime example of this;

“…the first signs are positive, we’ve had one scan and it does seem to show that the cells that are there are slowly decreasing in the activity that they’d shown…there is still an area which shows disease, but that shows reduced disease since the proton, so every two to three months she’ll have a scan, an MRI, or whatever they do, and then every two to three months she’ll be scanned for probably a couple of years, then hopefully it will go to six months and then maybe nine monthly, but they’re looking at a 20 year plan, which is pretty long obviously, it’s basically, ‘cuz it’s such a rare condition that there isn’t a lot of data about it, you know, someone with breast cancer, they know how it behaves, but with this, they don’t really know how it behaves, ‘cuz it’s very strange and rare form of cancer, so they have to obviously check…”

Whilst the first set of scans, post-PBT, are positive and show signs of the tumour dying, Claire explains that there will always be need for her daughter, Emily, to be monitored regardless. Whilst this is evidently a routine process for all patients involved in this study, adding to Claire’s concern is the rare nature of Emily’s tumour and the consequent lack of data about its

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12 For the mother at odds with these accounts, her son’s post-treatment scan showed that treatment had not worked, and an alternative course of treatment was being pursued.
behaviour which means that Claire and Emily, and even the medics involved, cannot be certain about the outcome of treatment and the tumour’s behavior. Featured in Claire’s account is a future narrative which involves routine surveillance and an unknown element about how her daughter’s disease may potentially unfold. The requirement to monitor the tumour over time and uncertainties about the tumour leaves no room for any certainty regarding Emily’s recovery, for the risk of recurrence means that the shadow of disease remains and is extended to her future. This is echoed by other parents as well, where Michelle for example explains that her son, Peter, has received scans showing that the tumour is static and stable, but he will be “monitored for the rest of his life pretty much”.

Peggy also speaks of the routine post-PBT check-up tests and scans that her son, Ashley, must undergo. Ashley is doing well and has received a clear scan, (he completed his proton treatment four years ago). Despite this however, Peggy suggests that the next routine scan could possibly indicate the return of his tumour, and she therefore does not agree with those around her who question her concerns despite Ashley’s clear scan. In the extract below she talks about the notion of ‘scanxiety’, which is the worry and anxiety experienced in the lead up to and the outcome of each scan:

“…when we got that first no evidence of disease scan on the 8th October, that was it, a new word that comes into oncology parents’ vocabulary is ‘scanxiety’, scanxiety is the lead up to those scans... and no body apart from fellow oncology parents understands that, the health professionals don’t, your family don’t, your direct friendship group don’t, erm, the only people that understand you are fellow oncology parents…”
Although Ashley has received a scan indicating no evidence of disease, for Peggy, the fear of recurrence and concerns about Ashley’s health remain intact. Peggy goes onto to explain that her parents struggled to understand, why in spite of Ashley’s clear scan, she still remained active and connected with other families through social networking. Explaining that only other oncology parents can understand and support her, Peggy also states that she relies on her connection with the treating doctor at the proton centre, who is receptive to her requests, in order to ask questions about Ashley’s tumour and talk about the proton side effects with her. Similar to Ashley, Mim, Carol’s daughter is also in remission. Carol speaks about Mim having received a scan indicating that the tumour is dead, however her contention is that the routine scans are insufficient and ought to be expanded. Carol fears that the scans, which are limited to the affected limb, may overlook the occurrence of cancer in a different limb;

“…’cuz you just don’t know, you know, will it come back there? could it come back somewhere else and although she’s monitored every 3 months and she has a scan, but they only just monitor her leg, and my concern is well, it could come back anywhere, you know what I mean, so that really does worry me, but I guess you can’t live your life like that…”

It appears that the routine medical surveillance and screening positions the child in an ‘at risk’ state, albeit the no evidence of disease, and leads to these parents’ increased uncertainty and vulnerability towards cancer, in spite of clear scans and positive results. In the above accounts, parents speak of an uncertain future marred by the fear of cancer recurrence and the need to undergo continued observations and check-ups. This sense of ambiguity and uncertainty is common to cancer survivors’ accounts; where they are generally not seen as cured, but rather in a state of remission (Roberts and Clarke 2009, Frank 1991). The culturally charged nature of cancer and the association of the disease with death is also thought to influence patients’
perception of the disease and treatment outcome (Bell and Kazanjian 2011); this is explored in further detail in the next sub-section. Peggy suggests that ‘scanxiety’ is a vocabulary which describes the feelings of an ‘oncology’ parent, i.e. the parent of a child with cancer, suggesting that this feeling is unique to the disease.

It appears that for some parents the routine post-treatment surveillance acts as a double-edged sword; whilst it provides assurance about the status of the child’s disease, it also places the child in a position of being at risk and their parents in a state of vigilance. In their study, Bell and Kazanjian (2011) also found that the continuation of diagnostic tests following treatment, caused these men to essentially view their cancer as incurable and chronic in nature. According to the authors, disease surveillance facilitates the perception of the ongoing ‘presentness’ of cancer, which heightens the uncertainty that cancer survivors experience. This research has demonstrated that these subjective experiences of cancer survivorship are also extended to the patient’s parent/carer. For Peggy and Carol, although their child has received a clear scan, it is apparent that the routine tests contribute towards their anxiety and the perception that the disease may return.

8.2.2 Uncertain Futures: Fear of Disease Recurrence

The fear of relapse and the notion that cancer is omnipresent is echoed by many parents, even when their child is doing well. In the extract below, Kelly speaks of the assurance provided by the routine monitoring of her daughter, Zara, but she also speaks of an unknown future in terms of her daughter’s illness;

“...they’ve mentioned that obviously she will be followed up, probably for the rest of her life in some capacity, a lot in the early time and then probably less, so she
will be monitored, which is ‘gunna give us reassurance ‘cuz that’s what we worry about, ‘cuz obviously the nearer we get to, I mean now we’re, we never thought we’d get to this bit and we can see an end in sight, which we didn’t think a couple months ago, but then, but it’s like a whole new sort of territory, ‘cuz now it’s, what happens later sort of thing!, so that’s scary as well…”

Notable in Kelly’s account are the different milestones she alludes to. Kelly indicates nearing a milestone where she states, “the nearer we get to”, and suggests that en route to this, ‘end point’, they have arrived at “this bit”, which is gradually edging them closer to the end. Whilst Kelly talks about seeing an “end in sight”, she steers away from this mapped out path and talks about the future as a “whole new territory to contend with”, where there are unknown elements. This unknown future effectively leaves Zara’s illness trajectory open-ended. Kelly goes onto explain that contrary to the expectation that treatment puts an end to illness and is followed by a return to full health, the worry and long-term fears never leave her as a mother and “it (cancer) is never over”;

“…you know, people are like, ‘she’s ‘gunna have treatment, she’s ‘gunna get better’, but they don’t understand the long-term fears that you have, you know, ‘cuz everyone just says, you know; it will be over soon, but it won’t be over! Not in my head it won’t, it won’t be over and other people don’t get that. It’s only parents that are going through the same thing that get that your worry doesn’t finish, it’s always ‘gunna be there…”

Elsewhere, Carol and James explain that they must not get complacent about their daughter’s health. Although their daughter, Mim, is doing well and is in remission, (she completed treatment over a year ago and has had a clear scan), James and Carol worry that Mim’s tumour may grow back;
“James: …over here, the parents we meet, like Mim is in remission, but you meet parents whose children have been in remission, but it’s come back, so it’s all, it’s always at back of your mind,

Carol: always back of your mind, and I feel sometimes you mustn’t get complacent, … she’s so well, you know, you kind of feel upbeat all the time with her, but I’ve learnt not to get complacent, ’cuz you hear, we haven’t had an experience where she’s gone down, but there are families where that becomes, …you’ve got to keep positive, you’ve got to keep thinking everything will be fine and for us it has, you know, but yeah, it’s always going to be at the back of your mind …”

Kelly, Carol and James suggest that the worry of cancer returning is always at the back of their minds. As discussed above, in the previous sub-section, the culturally charged nature of cancer contributes towards perceptions of the disease and treatment outcome (Bell and Kazanjian 2011); cultural connotations may therefore add to and exacerbate these parents’ concerns. Additionally, the experiences of other patients also contribute to and inform these parents’ concerns. James mentions meeting other parents and Carol talks about other families’ experiences, and so it appears that their fears are partly founded upon the experiences of other children who are in a similar situation to their daughter.

8.2.3 Uncertain Futures: Proton Treatment Efficacy and Related Side Effects

The role of technologies in creating uncertainties has been noted in the literature, where the main focus has been on the role of diagnostic technologies (Gardner et al. 2011, Jutel 2011, Blaxter 2009), although the role of treatment technologies as a source of uncertainty has also
been noted (Parry 2003, Cohen 1995). It is suggested that whilst advancements in medical technologies have improved long-term survivorships, poor understandings about physiological sequelae and unknown elements about future quality-of-life has created room for uncertainty (Parry 2003). This short sub-section is based on parents’ uncertainties in relation to proton therapy. Patients were diagnosed with a variety of tumours, but the common feature of their experiences is proton therapy.

Kim and Tom explain that three-years post-treatment, their daughter, Chelsea has done well in her follow-up appointments and has not had any complications. However, they point out that there was and remains an unknown quantity about the treatment, which leaves them unsure as to how the future may unfold for her. They explain that although Chelsea’s tumour is stable and she is in relatively good health, the information provided by their doctors has shaped the way they anticipate the future to unfold; this is explained by Tom in the extract below.

“...yeah, the things they (doctors) said obviously, in terms of the, erm, side effects long-term, that they did say to us that ‘cuz it’s quite a new treatment there isn’t the research there for it, so they said, initial signs are all very good for it, but going for, what could happen say in 10, 20, 30 years down the line, they did explain that there isn’t really the research there to be able to tell us…”

Similar concerns about the novelty of treatment and subsequent lack of information about its future prospects are also shared by Claire;

“...it’s quite a new treatment and so obviously I’m thinking, well what happens if 20 years down the line they discover actually this is what it causes 20 years on…”
As mentioned previously, in section 8.2.1, Claire’s daughter, Emily has a rare tumour. In an effort to better understand the tumour and its outcome Claire explains that they have been in contact with someone who was treated for the same type of tumour;

“Claire: …Emily has spoken to someone who had the same thing when he was 20, I think 23-24 and he is now 10 years on and he’s well and he had the same surgeon as Emily, but he was treated with the radiotherapy and the chemotherapy, but he’s well, so it’s hopefully, and he, he doesn’t seem to have any side effects, you know, from the radiation, erm, so hopefully with the proton there’s even less chance of side effects, and my main concern are her eyes, because it’s that area,

Interviewer: Has it effected it just yet?

Claire: No, not yet, they do say there is a 50% chance of Cataract, which could be corrected, but there is also a chance that, they say 5%, but I think it’s quite low, erm, of sight, not loss total, but reduction, and I said, that’s the only thing that I’m concerned about, erm, not the only thing, but, you know, they look at all your cognition levels and your endocrine hormone levels, but I think, they say it’s quite unlikely that she’ll have any of that, but, so, we’ll see, that’s the thing, it’s quite a new treatment, so you don’t know…”

Drawing from the experience of someone with the same rare condition, Claire and Emily try to formulate their expectations of the tumour’s outcome and Emily’s subsequent recovery from disease. However, Emily’s tumour has been treated with proton therapy and since this is a novel treatment Claire cannot be certain that Emily’s outcome will be similar to the other person who was treated with conventional radiotherapy. Uncertainties which arise specifically
in relation to the type of tumour are mentioned by other parents as well. In the previous chapter, Agatha and Louise both talked about concerns specific to their child’s rare tumour; similar to Claire’s daughter, their child’s tumour had responded well to PBT. However, the lack of research and information in relation to the tumour, and its behavior towards PBT, was a cause for concern for these parents, with Louise stating that there is very little research available on ‘proton and Chordoma’. In an effort to manage these uncertainties, these parents actively sourced information from other patients and families.

Whilst proton therapy is framed, within the documents, as an effective mode of therapy with limited side effects the accounts given by the parents suggests that the novelty of this technology and the consequent lack of evidence creates room for post-treatment uncertainties. In comparing her daughter’s case to the other person, Claire explains that she hopes the fact that Emily has had proton therapy, rather than radiotherapy, will reduce her chances of side effects. However, she largely remains uncertain about the outcome since the treatment is new and there is not long-term evidence. The anticipation surrounding what to expect and when to expect it casts a state of prolonged uncertainty. Additionally, proton therapy is largely used to treat rare and complex tumours. Uncertainties about the treatment are coupled with uncertainties about the tumour and its behaviour, and exacerbates these parents’ uncertainties. Uncertainty about the effects of treatment are also intensified for even the doctors are unable to provide any affirmative prediction.

This section has highlighted a range of uncertainties that parents talk about, following their child’s completion of treatment. Three areas of uncertainty, related to surveillance, relapse and proton treatment were observed in these parents’ accounts.
Whilst parents speak of marked signs of improvement, i.e. tumour disintegration and clear scans, it appears that routine surveillance and long-term medical plans involved in monitoring the child, extends the disease and their illness trajectory into the future. Disease surveillance is known to facilitate the perception of the ongoing ‘presentness’ of cancer, which heightens the uncertainty that cancer survivors experience (Bell and Kazanjian 2011). Whilst parents spoke of marked signs of their child’s tumour responding to treatment, they were also in a state of vigilance and uncertainty about what the next scan may reveal. For some parents, although their child was in a state of remission and had received clear signs, the routine tests contributed towards their anxiety and the perception that the disease may return. It is also noted that the nature of the disease, i.e. cancer, may have also contributed to these parents’ uncertainties. The possibility and fear of tumour recurrence was common to most parents’ account, where the experiences of other parents and families were found to contribute towards these views.

Proton therapy as a source of uncertainty was explored. As was demonstrated in Chapter Five (Discourse Analysis Chapter), proton therapy is widely depicted in the information leaflets as a highly effective mode of treatment and the overall side effect profile of treatment is downplayed across the documents. Where the subject of side effects is broached no specifics are offered and it is left to the reader’s discretion to decipher what is meant by the vague descriptions provided. Furthermore, the side effect discussion is primarily focused on the here and now of treatment and the post-treatment and long-term discussion takes a backbench. However, as it emerged in the interviews, the novelty of proton treatment and the absence of long-term evidence about treatment outcome and side effects leaves some parents feeling uncertain about the outcome and future implications of treatment. The rare nature of the child’s tumour and the lack of research in relation to this also adds to these uncertainties, where parents were unsure as to how the tumour and PBT will behave together. These uncertainties manifest
themselves in the child’s future, where parents talk about being unsure of what to expect and not knowing whether treatment has been effective. The uncertainties which loom in their child’s future means that there is no clear line marking a turn to recovery, and the illness trajectory is extended into the future. It became apparent that in an effort to manage these uncertainties, parents rely on information sourced from other parents and families, largely accessed via online communities, as well as information from their doctors.

8.3 Post-Treatment Experiences of Illnesses

In this section interviewees’ accounts of their child contending with some of the after effects of treatment and disease complications are discussed. All interviewees spoke of their child living with some form of health complication or side effect, post-treatment. Some of these constitute new forms of chronic illness in their own right, whilst others are short-term impairments or disabilities. Living with and managing these health issues means that the child’s health remains and continues to be compromised, and that recovery from illness is not achievable. In this context, recovery is taken to mean recovery from the physical ailments and a return to the pre-illness status quo (Parson et al. 2008, Radley and Taylor 2003).

Reflecting on her son, Mason’s, state of health whilst on treatment, Rosalin explains that other than a compromised appetite and sensitive scalp, “he was really well actually”. However, when speaking of the present, she speaks of a range of side effects such as, “hormone things”, fatigue, diabetes and an underactive thyroid which Mason is suffering from. These health complications lead her to say that Mason is “less well”, post-treatment;
“...he came back and he was lucky and he went straight into school fulltime, and because he looks ok, you know, I think people do tend to think, ‘oh he’s had treatment, he’s fine now’, and you’re like, well no, you know, and actually he’s been less well since he’s come home than he was when he was out there... sort of feels like a bit more like when you’ve come back, you know, he was so well and now he’s just not as well as he was...”

These health complications experienced post-treatment by Mason, and other children alike, push them further away from achieving a fulfilled sense of recovery. This is contrary to the common expectation and belief held by ‘people’, that Rosalin refers to and which Kelly mentioned in section 8.2.1, that treatment is followed by a return to health. Contrary to this expectation it is evident, from the post-treatment experiences recounted by the parents, that achieving this sense of recovery is in fact impossible due to ongoing health complications.

Parents also talked about what it meant for their child to live with some of the proton therapy post-treatment side effects. Living with some of the side effects disrupted their child’s lives and daily routines. Graham and Heather’s account was loaded with talk about their son’s ongoing health complications arisen from proton treatment. The couple were interviewed close to four and a half years post-treatment, and proton therapy had not yielded the desired outcome for their son. They explain that rather than the tumour ‘shrinking’, which was the intended outcome of treatment, the tumour has always remained in a stable condition. Their son, Charlie, has routine scans every four months and they are in a position where they should “watch and wait”, with Heather stating that they are actually expecting the tumour to re-inflate;

“...and they (doctors) did say, you know, it will happen, it will re-inflate and they will have to look at what they can do, I don’t think that can do a second
Transsphenoida surgery, I don’t think, I think they might have to go down through his head, but the idea was that it’d (PBT) stop it and give him 20-30 years, it hasn’t…”

There is no disputing the fact that the failure of treatment to yield the desired outcome has barred Charlie of any sense of recovery; the tumour remains intact and Charlie’s status as a patient remains in place. In addition to this however, Charlie’s parents also draw my attention to several health issues and side effects which their son has experienced post-treatment, some of which are still affecting him four years down the line. Charlie’s eye-sight has been compromised, which has gradually deteriorated further past treatment, he has no pituitary gland, no thyroid function, suffers from Hypothalamic obesity as well as fatigue. The post-effects of treatment have worsened his health and some of these issues, most notably his compromised eye-sight and fatigue, have disrupted his daily life. In the extract below, the couple are recalling events which took place four years ago, immediately after treatment;

“Interviewer: So, when you came back from proton, what happened then?

Heather: right, when we came back from proton, erm, everything was fine, we came back middle of August, Charlie went back to school in September and he’d been back at school 2 or 3 weeks and then Somnolence syndrome (excessive daytime sleeping) hit him, where he’s just really really tired, and it’s an after effect of proton, but a sign nobody told us about…..so we came back and he had Somnolence syndrome and it went on, it just came out of the blue one day and it went on for about 6-8 weeks…”

Four years on and Heather explains how the health issues persist and Charlie’s fatigue remains intact, this has especially compromised his education;
“... he’s quite tired, we’ve had to pull him out of school on a Wednesday afternoon ‘cuz he’s just so tired, erm, we were hoping to leave it to the end of the week, but because he’s doing his options and his exams, we’re about to drop 2 of his options, just so he can cope with his homework and everything, so he has learning support and goes there to do his homework, so it’s having more of an effect on his school work right now than it ever has, .... His work hadn’t really been effected, but now he’s really struggling with just kind of keeping going at everyday life....”

Somnolence syndrome is an after effect of proton treatment, however no one had prepared or informed Heather and Charlie about it. Here, Heather recalls the moment when Charlie’s oncologist offered her an explanation for his symptoms;

“...we went back to the Hospital, as soon as he was unwell we contacted the hospital and we went to see his oncologist who said, ‘oh yeah, that’s somnolence syndrome’, as if you know, it’s the most normal thing in the world...”

Somnolence syndrome is mentioned by some of the other families as well, and in these instances they too suggest that they were unaware and unprepared for this after-effect of proton therapy. Below, Louise explains how a week after arriving home from treatment her son experienced significant levels of fatigue, which she was unprepared for;

“Louise: yeah, solemnness (sic), erm, it’s, it’s erm linked to proton, where basically they experience extreme tiredness, so, they can sleep for like 20 hours,... yeah, and I wasn’t really prepared for it, erm, he was generally tired and he rested after proton, so he had those rest periods but then coming back here it didn’t really kick in and doesn’t technically kick in until it’s about 4-6 weeks after the last treatment, erm, and that was during the school holidays so it was fine for him, but
I remember driving him to hospital for one appointment and bearing in mind this is a 12 year old child who’s never fallen asleep in the car since he was a baby, literally he was comatose, I was thinking how am I ‘gunna get him out of this car for his appointment, basically I did, but he was like, there was nothing, just like this for weeks wasn’t he,

Interviewer: And you weren’t prepared for it?

Louise: no, not told about it, wasn’t prepared for it, erm, it’s just a period that they’ve got to go through,...”

These examples suggest that some of the side effects experienced by the child, post-treatment are unexpected with parents explaining that they were unprepared for them. In the section prior, it was demonstrated that unknown features of PBT means that parents cannot be certain about what to expect for their child, and are unsure about how the future will unfold. In the examples of Louise, Heather and Graham, they too were unprepared and uninformed about this side effect of treatment.

The accounts relayed here by the parents are at odds with the picture presented within the documents, analysed in Chapter Five. With the focus largely being on the treatment’s capabilities, a post-treatment narrative is absent in the documents, and discussion of treatment side effects are limited, or sometimes absent. However, in their interviews parents talked about a range of health complications experienced by their children, some of them directly related to PBT, and reflected on the way these have impacted their child’s daily lives and routines. Living and managing these health issues means that the child’s health remains and continues to be compromised.


Chapter 8: Post-treatment Accounts; Uncertain Futures and Recovered Pasts

8.4 Recovering Normality Following Proton Treatment

Returning to normal following treatment is an important goal, for both cancer patients and their families (Baker 2016, Woodgate 2006). The ability to return to normal or at least maintain some level of normality is considered an important element of recovery (Balmer et al. 2015). The opening of this section looks at the way parents frame accounts of their child’s recovery, as their ability to reengage and recover routines, practices and identities which constituted the norm, prior to their diagnosis. In spite of their child’s ill health, this aspect of the child’s recovery is benchmarked against a prior-self and is gauged by the ability to resume normal activities. Following this, aspects of recovery pertaining to parents’ own experiences are explored. It is demonstrated that recovery from childhood illnesses is dyadic and shared between parent and child.

8.4.1 Child’s Recovery

Some parents talked about their child returning to nursery and school following proton treatment, and viewed this practice as a marked sign of improvement. In parallel to speaking about her ongoing fears for her son, Dean, and his enduring health complications Judy also suggests that he is doing well, where he has managed to return to school; 

“...I think, I’m so scared for him, but saying that, he started school last September and initially he was doing 3 days, he’s now doing 4, and although he struggled terribly the first term, he’s done so well, he’s got his own little friends and still has issues,...”

Although Judy remains concerned about Dean’s health issues she seems to view his ability to attend school four days a week, up from three, and socialise with his friends as a sign that he
is doing well. Elsewhere, Rochelle talks about her daughter, Mim, managing to return to pre-school. Rochelle compares Mim’s current ability to attend pre-school to the period she was unable to, due to her chemotherapy, and explains that this reversion has instilled a sense of normality;

“…obviously she couldn’t go to pre-school, that sort of thing because of, in the high intensity chemo, it’s just too risky for her to catch something through school children, now (post-PBT) she is back at her pre-school a little bit more, which is really good, and that brings on, kind of a sense of normality…”

For parents such as Judy and Rochelle, the ability of their child to return and engage with routines which constitute normal is viewed in a positive light and, for them, is indicative of a return to normality, following the acute phase of their child’s illness and treatment.

Claire also refers to the notion of normality when speaking about her daughter. The notion of normality which this mother speaks of is not only limited to a return to practices which constitute normal, but also appears to involve a return to a prior normal-self where she talks about her daughter returning to “her normal teenage self”. Opening my interview with Claire, I asked her to provide a brief background to herself and her family and to talk me through the lead up to her daughter, Emily’s, diagnosis. Claire responds by pronouncing her family as a “pretty normal average family”, and describes Emily by listing traits typically associated with a teenager, “Emily has always been very outgoing, very independent, erm, you know, always out with friends, never at home”. Further down the interview, when I ask Claire ‘how are things now?’ (post-treatment), her response is as follows:

“…Emily is at college and she loves it and I’m happy that she’s getting back to her normal teenage life, erm, so that’s good, if she’s happy, you know, I’m happy;
erm, but, yeah she hates having to go into London for an appointment, she hates the scans and she hates the thoughts of having to have more surgery or anything like that, and as she gets older she’ll obviously be able to deal with it all more and hopefully it will just be scans and nothing else...”

Whilst continued interaction with the medical sphere, the possibility of further surgery and an uncertain future in terms of the tumour’s progression remains intact (see also section 8.2.2), Claire asserts that Emily has at least recovered some aspects of her pre-diagnosis-self; Emily is back at school and is getting back to, what her mother views as, her normal life and teenage self. It appears that in these instances the child’s pre-diagnosis life, and parents’ notions of what constitutes normality for their child, provides a yardstick against which non-physical aspects of recovery are measured. Regardless of the status of the disease and ongoing health complication, these parents speak of aspects of their child’s life which assert normalcy, and are based on a positive outlook. This speaks to research carried out by Dowswell et al. (2000) on adults’ recovery from stroke, which frames recovery as something personal and perceived by patients in terms of the degree of balance between their lives before and after stroke, regardless of physical function. In these instances, it is the patients’ caregivers who are framing these notions of recovery, based on what they perceive to be normal for their child.

In my interview with Rosalin, she too draws on her son’s former life, prior to diagnosis, in order to construe his post-treatment status. Throughout the interview, Rosalin repeatedly alludes to her son, Mason’s, love of basketball and it is clear that his passion for sports forms an important aspect of his life and of who he is. For example, Rosalin explains that Mason’s love of basketball made the job of persuading him to have treatment in America much easier, and his current choice of secondary school is based on their basketball team and PE coach. In
Rosalin’s view Mason’s ability to play sports, following his proton treatment, is a marked sign of improvement and signifies a return towards normality;

“...he’s back doing lots of exercise like he did 2 hours training last night, he’s doing a lot, which, he’s probably not back where he was originally, erm, like strength wise and fitness wise kind of things, but I know from other people, I’m just thankful ‘cuz he’s doing a lot that other people in his condition couldn’t do, you know...”

In parallel to utilising the notion of a prior-self, Rosalin also manages to establish a sense of normality through the process of normalisation, where she draws on a comparison to others with the same condition in order to normalise Mason’s current status. Normalisation is defined as attempts which serve to maintain a normal life and sustain qualities that make up who people are (Weiner 1975 in Sanderson 2011). In experiences of illness, normalisation is employed in order to re-establish a sense of normality following from disruption brought about by diagnosis (Locock et al. 2009). Mason’s pre-diagnosis life and his love of playing sports is used as a benchmark for Rosalin to ascertain a sense of normality. Although Mason is not back to where he was originally, his abilities are juxtaposed against others who are in a similar situation to him, and therefore normalised by his mother.

Based on Rosalin’s account, and the following example below, recovering the ability to perform tasks and hobbies, which were hindered or postponed throughout the acute phase of the illness and treatment, are important markers of recovering some sense of normality. The following extract is from my interview with Ralph and his son, Lee 13, who was also present in

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13 Lee was 15-years-old when he underwent proton treatment. At the point when I interviewed his father, he was 17-and-a-half. Whilst I did not formally set out to interview Lee, he was very eager to talk and his father also encouraged him to take part in the conversation. I provided Lee with an information sheet and asked him to sign a consent form.
the interview. In the early part of the interview after establishing that it is over two and a half years since Lee completed his treatment at the proton centre in America, Ralph explains;

“…he’s (Lee) doing well, but there still are worrying times, there are times when he’s obviously poorly, but most times he’s not, he’s a normal, lovely, annoying teenager and he’s good on the guitar, that was one of the things that worried us, because we thought the tremor might be stress because he had mock exams coming up, erm, GCSEs, and you think is he just worried about the exams that he’s psychologically starting to shake and thinking he’s unable to do them, but the thing was, guitar never worried him, it was his happy place, he’d pick up the guitar and play with this eyes shut, you know…”

This is then followed by a chronology of diagnosis and treatment and their experience at the proton centre. Leading up to the closing of the interview, I then ask Lee;

“Interviewer: So, you’re back to playing the guitar, that’s great…

Lee: I’m trying to, yeah, I got a Gibson,

Ralph: Soon as he’s up to it he can play that,

Lee: We bought it out in the states and I haven’t played it yet, ‘cuz I’m waiting til the point where I know I’m as good or better than I was before, I mean I tend to play different stuff now, I tend to play more kind of BB king blues, before I used to try and play faster stuff, but I don’t try that anymore,…”
I interviewed Lee and his father at their home. Lee’s collection of music and his guitar are in the corner of the room where the interview took place, Lee also brings out his treasured Gibson guitar and strums a few notes once the interview is finished. His passion for his music and guitar is evident, where both father and son talk about their joy at being able to travel to various music hot-spots whilst in the States for treatment, and the various music experiences Lee has been granted via different charities; the highlight being Lee’s trip backstage to meet one of his favourite musicians. Lee also spends some time after the interview recommending the films I should watch based on their musical score. It is evident that music is a passion of Lee’s, and his ability to once again play the guitar is important to both himself and his father. Lee’s ability to play the guitar is viewed by both father and son as indicative of a return to his normal-self, despite the health complications which persist. This case is at odds with the other examples, since the voice of the patient, i.e. child is also included. Whilst the focus of this thesis is on parents’ accounts, I chose to include this excerpt since it highlights the fact that young people and children want to be heard, and can offer rich insights into their views and experiences.

Based on the accounts above it is evident that a tangent to recovery exist, which sits outside the medical realm and physical aspects of illness. The notion of recovery is benchmarked against a prior-self and is gauged by the ability to resume normal activities. The child’s ability to return to school and engage with practices and hobbies, which had been hindered and disrupted by the acute phase of their illness, are regarded by parents as marked signs of improvement and which instil a sense of normality. This is in line with research carried out with adult cancer patients, where the ability to return to normal or at least maintain some level of normality was considered an important element of recovery (Balmer et al. 2015). A sense of recovery was also achieved by parents, through the process of normalisation, whereby
normalcy was demonstrated by juxtaposing less able peers with the same condition against the abilities of their own child.

Albeit from a carer/parent perspective, these findings support research which conceptualises recovery as complex and personal, and based on standards of normality. Recovery is personal and intertwined with dimensions which constitute a person’s identity; the child’s pre-cancer lives provided a yardstick against which recovery is measured by their parents.

### 8.4.2 Parents’ Recovery

This section is focused on interviewees’ reflections of their own lives post-treatment and is based on their responses to my general question about what impact has their child’s illness had on their lives. Contrary to above, where parents framed their child’s recovery as a perceived ‘return to normal’, in reflecting on their selves, some parents spoke of a “new normal” and adjusting to this, whilst others noted no change to their lives. Some parents talked about recovering their parental identity towards their other children, this is explored in the later part of this section.

**Recovering Normality**

In my interview with Lisa and Jonathan, Lisa alludes to the notion of “new normal”, but asserts that their life currently remains unchanged;

“...I think, ‘cuz us not having to have the chemo, I think the new normal hasn’t been as bigger, for us, we’ve been able to kind of carry on as normal, but I think, obviously the new normal is ‘gunna involve a lot more scans and does involve
more hospital appointments and stuff like that, erm, at the minute, I think I’m able
to kind of compartmentalise, so we have normal, and, yeah, I’m sure when it
comes to scan times, there will be a sort of anxious time around,…”

Lisa and Jonathan explain that they came across the concept of a ‘new normal’ at the very start
of their daughter’s journey, i.e. diagnosis, in an online blog forwarded to them by a family
friend whose child had also been diagnosed with a CNS tumour. Lisa explained that having
read the blog she was very afraid of what a new normal meant;

“…the whole, this new normal thing and that your life will never return to normal,
and that made me feel loads worse after reading that I think…”

The couple go on to explain that since Emily is so well, the new-normal has not affected their
lives, but anticipate that this may be something they encounter in the future;

“Lisa: I don’t know if the new normal thing has hit me yet, maybe that’s in the
post, but I think because she’s so sort of well in herself, you kind of just,

Jonathan: yeah, sometimes it’s hard to, it’s easy to forget, you know, that that
issue’s there because she was so well throughout the proton treatment, weren’t
she? She didn’t tire as much as some kids did, erm, she didn’t have any side effects
really, the hair loss only really came at the end…..”

Lisa and Jonathan were interviewed three months post-PBT. The fact that their daughter
remains well, aided by the fact that chemotherapy was not required, means that the family has
managed to hold onto their ‘normal’, post-treatment. However, the possibility of a new normal,
consisting of routine appointments and anxiety concerning the outcome of scans, looms in their
future. Lisa and Jonathan’s state of normal and new normal are both positioned as dependent
on their daughter. A similar sentiment was evident in Kelly’s account, in section 8.2.2, where she spoke of seeing “an end in sight”, but also spoke of the future as a new territory to contend with. There is a shift in her account which resonates with Jonathan and Lisa’s account where they contemplate the unknown future and having to deal with a possible ‘new normal’. Jonathan and Lisa’s account also draws attention to the non-medical voices which play a role in shaping parents’ future expectations for their child, where they appear to be drawing from the information provided by other oncology parents, in an online blog, in order to form their expectations of the future. The role of other parents’ knowledge and advice was discussed in the previous chapter, and earlier above when parents talked about managing their uncertainties.

In contrast to Lisa and Jonathan’s account, Rochelle talks about life never being the same again;

“…your whole life, erm, your life as you know it, erm, isn’t the same, it can’t be the same, my husband couldn’t work, he was lucky in that his company supported him and gave him compassionate leave, erm, because we spent so much time in hospital…. I was on maternity leave and haven’t gone back to my job, erm, since, because it doesn’t feel, it doesn’t feel right to do that, given there’s so many hospital appointments and so on,…”

Whilst in this excerpt Rochelle reflects on life not being the same again, earlier in her interview (see section 8.4.1) she spoke of her daughter’s return to pre-school and how this instilled a sense of normality. However, it appears that Rochelle has personally been unable to fully recover from the disruption brought about by her daughter’s illness, and life is no longer the same as it used to be for her, and her husband. The disruption appears to be largely related to both parents’ occupational roles. Whilst her husband was initially unable to work, he has now returned to his job, however Rochelle has made the decision to not return. This behavior could
be partially attributed to the gender differences apparent within the division of caring tasks between parents.

Michelle also iterates similar feelings where she explains that the illness disrupts any notion of normality. Michelle had been talking about the problems she had faced at work and how difficult it had been to juggle all the different appointments and the period of treatment abroad, with her job. At this point, she talks about being blissfully unaware of the existence of cancer parents until you become one and face the struggles. Below, she talks about how her son’s diagnosis changed her life;

“Michelle: … it (cancer) changes your normal, it changes normal quite massively”

Interviewer: and is it difficult to get back to that normal? Do you ever get back?

Michelle: You never get back to that normal it was before, your normality is irreparably changed, now we’re trudging along right now, he’s having his scan every 4 months…”

Whilst for a very small minority of parents there appears to be no disruption to their normality, some of the parents speak of life not being the same, post-diagnosis and treatment. These parents talked about the disruption brought to their normal routines as a result of their child’s illness, and how life will never be the same again for them.
Some parents talked about new normal and mentioned how this can be difficult on their other children. The segment below is focused on parents’ accounts involving their other children and the impact their child’s illness has had on their parental identity.

**Recovering the Parental Identity**

Fourteen of the parents interviewed had more than one child. Whilst the primary focus of the interviews was on the child who had undergone treatment, parents also spoke of their other children and reflected on some of the difficulties and challenges parenting a sick child has had on their other children, and their parental role towards them. Parents were aware of the way siblings might feel because of changes to family practices and the focus being dedicated to their sick child, and spoke of the adjustments they have made in order to address these issues. Parents were worried about their other children feeling left-out and explained that they made a conscious effort to recover and maintain the balance of parenting towards them. These concerns were most acute in the families who had not managed to travel collectively to the States and who had been separated for a long duration of time. Parents explained that following the end of treatment and returning home from the proton centres, they made effort to spend time with their other children and maintain their relationship with them. The following passage is from my joint interview with Graham and Heather. Heather had travelled to America with her son Charlie, whilst Graham remained in England with their three other children. Father and children joined Heather and Charlie during the last two weeks of treatment. Here, Heather talks about the impact of the overall experience on her other children, specifically her daughter, and explains that as parent she had to make adjustments in order to address these concerns;

“Interviewer: …you mentioned that there’s now a new normal, could you tell me about that,
Heather: yeah, the new normal, erm, I think it’s particularly hard for the other children, erm, I think it was very hard after I’d been away for proton, particularly for my daughter, she really struggled, I used to work evenings and weekends and when I got back I carried on doing that, but you know, for my daughter, I was at home a lot during the day with Charlie, and then when she’d come home from school I’d be going out to work in the evenings, so it became very difficult and I gave that up, so I think, she just missed me, she missed me, and also, the focus is on the child’s that ill, but there are, I always say to people, you know, 3 other children in the family as well and it’s tough on them, it’s tough on them, even if you might be going out to dinner one evening and then Charlie is ill and too tired to go out, then we don’t go out, so even just down to that, it’s tough on them, you know, I do feel they are the forgotten heroes, the siblings, you know, there’s lots of charities and things that want to do things for your child, but, you know, it’s the others as well,....”

Rosalin is also conscious of the effect her absence, whilst abroad for Mason’s treatment and him having more of her attention, has had on her other son, Mike. She explains that in wake of her return from America, she has made effort to spend separate quality time with Mike. Rosalin talks about wanting to know how other people deal with the impact of the illness on their lives; it becomes apparent that by people, she means other oncology parents. When I ask her what impact Mason’s illness has had on her, her response is based on her concerns about Mike and her parental role towards him;
“Rosalin: I like to speak to people who are going through it as well just so that you, you know, just to get how they dealt with and what impact it had on them and things like that,

Interviewer: Uhmm, what impact has it had on you?

Rosalin: It’s like, I, it just kind of does take over your life really because as much as he’s well, it’s kind of always there, you know, in the background, and I do try and let him do normal things, I don’t want him to feel like he can’t do that. It is difficult, like this week I had a phone call saying can you come to B hospital this week, so I’ve had to say to work, erm, I need, I’m not going to be in next week, so obviously your children always come first,.... So that’s difficult and it’s difficult for like Mike as well because he was, I left him effectively for, well he was with his dad, but I wasn’t here for 8 weeks, well 6 weeks, 7 weeks without me and then I’ve got to go again next week, so he’s saying, ‘I don’t want you to go’,....

Interviewer: Yeah, how old is he sorry?

Rosalin: He’s 9, and you know, he said to me, ‘oh it’s always about Mason’, and I’ve said, well, yeah, it is because Mason is not very well and we’d much rather Mason was well.... Obviously, you try to treat them the same, but, but you know, it’s a bit more about Mason, but I don’t want it too much to impact on him that he feels he’s missing out, you know, missing out on stuff because of Mason really, so we do try...”
This short section has drawn attention to the effect of a child’s illness on wider family members, i.e. siblings. Heather describes siblings as the ‘forgotten heroes’; ‘hero’ is usually a term reserved to describe a patient and their battle to fight and overcome their disease. In this instance however, Heather is assigning it to her other children who have also had to endure some difficulties as a result of their brother’s illness. The effect of their child’s illness on their siblings was mentioned by many of the parents, where they described their other children becoming jealous and upset as a result of the sick child receiving all the attention. Recognising these issues, parents spoke about the importance of achieving an identity as a parent to all of their children, and not just the sick child. In section 8.4.2, parents spoke of a new normal and coming to terms with their identity as a cancer parent, in this section however parents spoke of their identity as a parent towards their other children and the importance of recovering and maintaining this identity. The demands and disruptions brought about as a result of the child’s diagnosis and the need to be absent from the family for treatment, hampered their relationship with their other children. Following the acute phase of illness and returning home, parents worked on recovering and maintaining these relationships. Similar to concepts discussed in section 8.4.1, where parents spoke of their child recovering their normal routines and prior-selves following the end of their treatment, parents also place importance on their own ability to recover and maintain their identity as a parent. These accounts corroborate findings which postulate recovery as the ability to achieve continuity of identity and relationships. However, in this instance it is not the patient, but the carer/parent, which is the focus of attention.

8.5 Summary

This chapter has examined parents’ accounts involving post-treatment experiences. The following research questions have been addressed; ‘What uncertainties do parents face in
relation to their child’s experience of illness?’; ‘What uncertainties do parents face in relation to Proton Beam Therapy?’; ‘How do parents understand and form views of their child’s recovery, following proton treatment for a cancerous or benign tumour?’ and ‘How do parents speak of their own recovery, following their child’s experience of proton treatment?’

Three areas of uncertainty related to medical screening and surveillance, fear of relapse and proton treatment were observed in these parents’ accounts. Whilst parents spoke of marked signs of improvement and clear scans, the routine surveillance and long-term medical plans involved in monitoring their child were found to have facilitated the perception of the ongoing ‘presentness’ of cancer. Similar to findings reported by Bell and Kazanjian (2011) surveillance medicine seemed to blur the lines between risk and disease state, heightening these parents’ uncertainty. For the large majority of parents interviewed, their child had been diagnosed with a cancerous tumour; it was therefore noted that the wider discourse associated with cancer may have contributed to some of these parents’ experiences of uncertainty. The possibility and fear of tumour recurrence was common to most parents’ accounts, where the experiences of other parents and families were found to contribute towards some of these views. The rare nature of some of the cancers were also found to contribute to parents’ uncertainties, where they could not be certain of how their child’s tumour would behave. In some instances, the rare nature of the child’s tumour coupled with the novelness of PBT exacerbated some of these uncertainties. Uncertainties pertaining to proton therapy were noted in some of the respondents’ accounts; these parents explained that due to the absence of long-term evidence about proton treatment, they could not be sure about what to expect about the outcome of treatment and how their child’s illness may progress. These uncertainties were found to manifest themselves in the child’s future, resulting in there being no clear line marking the end of illness. It became
apparent that in an effort to manage some of these uncertainties, parents rely on information sourced from other parents and families, as well as information from their doctors, where possible.

Parents also spoke of a range of short-term and long-term health complications, post-treatment, that their child suffers from. Some of these issues were found to be an, unexpected, side effect of proton treatment with parents’ explaining that no one had prepared or informed them about. With a focus on the physical aspects of recovery from illness, and the notion that recovery means a transitioning back to a healthy person (Parson et al. 2008, Radley and Taylor 2003), it was found that this aspect of recovery is unachievable for some children. Despite these parents speaking about their child’s tumour responding to treatment, living with and managing further health issues means that the child’s health remains and continues to be compromised, and that recovery from illness is not achievable.

The accounts to emerge from these interviews are at odds with the depictions uncovered in the documents, and there are clearly gaps between the documents’ representation of PBT and users’ actual experiences involving treatment. Chapter Five demonstrated that proton therapy is widely portrayed in patient information leaflets as a highly effective mode of treatment, a negative outcome of treatment is unacknowledged, and the overall side effect profile of treatment is downplayed. Where the subject of side effects is broached the discussion is primarily focused on the here and now experience of treatment, and the post-treatment and long-term discussion takes a backbench. Overall, the information leaflets failed to engage with the patients’ experience of illness and treatment, and rarely admitted any uncertainty in relation to proton therapy. However, as it emerged in the interviews, children treated with PBT suffer from a range of treatment side effects; leading some parents to describe their child as being
more ill post-treatment. Parents also mentioned being unprepared to deal with some these health issues and the emergence of some side effects were unexpected and caught them off-guard. Additionally, parents also spoke about uncertainties pertaining to proton treatment, which left them feeling unsure about the outcome and future progression of their child’s illness. In an effort to manage some of these uncertainties, parents relied on information from other patients and their families. The importance of having access to the lived experiences of PBT was highlighted in the previous chapter as well, where parents spoke of their efforts to seek information about the reality of treatment from other patients and families. This highlights the value and need for information leaflets to incorporate the views and experiences of patients and users of the treatment, or to at least sign-post the reader to these sources of information.

Whilst parents spoke about ongoing health issues and uncertainties about the progression of disease and treatment outcome, barring a coherent sense of recovery from illness, a different dimension to recovery, framed as a return to normality, was uncovered in these parents’ accounts. Echoing research in the field (Grant et al. 2009, Godfrey and Townsend 2008), recovering the ability to partake and carry out tasks, which were hindered by the acute phase of illness and treatment, were regarded as marked signs of improvement and signified a return to normality. The child’s pre-cancer/treatment lives provided a yardstick against which these non-physical aspects of recovery were measured. For these parents, their child’s recovery was gauged by the ability to recover their past lives and identities. Nuances of this aspect of recovery were also found in parents accounts describing their own experiences.

Parents talked about and applied notions of ‘new normal’ to their own lives and experiences, with some parents suggesting that their lives will never be the same again, as a result of their child’s diagnosis. Parents spoke about their disrupted routines and lives, and also alluded to
their comprised role as a parent. These parents spoke about actively trying to repair their role as a parent towards their other children, who had been neglected due to the parents primarily focusing on the sick child. A core finding of this chapter is the assertion that parents subjectively experience an extension of their child’s illness. Whilst parents talk about their child contending with the potential implications of the illness in the future, they also state that they themselves ‘learn to live with cancer’. Thus, their child’s illness experience is extended to them and so is any sense of recovery. To this end, recovery from childhood illness is conceptualised as a joint venture, shared between parent(s) and child.

This research has also highlighted the different and varied voices which play a role in shaping expectations of treatment and recovery. Parents talked about relying on the subjective experiences of other families and parents in order to manage some of the uncertainties they experience, and to become better prepared about what to expect from treatment. Additionally, parents were also found to frame perceptions of their child’s recovery, through the process of normalisation, whereby parents would juxtapose less able peers with the same condition against the abilities of their own child.

Finally, it is apparent that some aspects of the recovery experience may be attributed to and shaped by the treatment and the unusual nature of the treatment regime. Despite PBT being depicted as an effective mode of therapy with minimum side effects, the uncertainties surrounding this novel mode of therapy influence the way recovery is perceived. More so, the need to travel a long-distance from home in order to receive treatment disrupts the family unit and impacts the parental role. Upon returning from America, some of the parents spoke of consciously repairing and recovering their role as parent towards their other children.
This chapter has established that recovery in the context of a proton family is multifaceted and an ongoing process. Recovery following treatment is not only limited to physical recovery, but involves biographical revisions and repairs. This notion of recovery and attainment of normality is not only limited to the sick child, but is extended and experienced by their parents and close family members.
Chapter 9: Discussion and Conclusion

9.1 Introduction

The focus of this thesis has been the experiences of parents of paediatric patients treated with a new type of radiation therapy, Proton Beam Therapy (PBT). In addressing this aim, the study set out to answer the following research questions: ‘How do parents view and understand Proton Beam Therapy?’, ‘How do parents manage decision-making involving Proton Beam Therapy?’, ‘What types of specialist expertise do parents of children treated with PBT possess?’, ‘How do parents acquire their specialist expertise?’, ‘What do they use their specialist expertise for?’, ‘What notion of parents is portrayed across information leaflets?’ and ‘How is Proton Beam Therapy depicted in the information leaflets?’, ‘How do parents understand and form views of their child’s recovery, following proton treatment for a cancerous or benign tumour’?, ‘How do parents speak of their own recovery, following their child’s experience of proton treatment?’, ‘What uncertainties do parents face in relation to their child’s experience of illness?’ and ‘What uncertainties do parents face in relation to Proton Beam Therapy?’.

This is a qualitative inquiry based on, joint and single, interviews carried out with parents of paediatric patients treated with proton therapy. 27 parents, eight fathers and 19 mothers, were recruited to the study via an online support group, as well as charities. Parents were interviewed about their experiences involving their child’s diagnosis, medical treatment and decision-making concerning proton therapy, as well as their post-treatment experiences. Additionally, discourse analysis of information documents, related to proton treatment, which are accessed by and made available to UK based paediatric families was conducted. The aim of this was to
reveal the privileged discourse embedded within the official accounts and to compare them to parents’ accounts.

In this chapter I draw together and reflect on the key findings from the preceding chapters, which have informed this study; these are outlined in section 9.2. This is then followed by discussion of the wider contribution of this research to sociological literature. Next, the strengths and limitations of the study are considered and outlined in section 9.4, followed by an outline of future research possibilities, in section 9.5. Some concluding remarks are offered in section 9.6.

### 9.2 Key Findings

Key findings drawn from this study are summarised in this section. These findings have been grouped into five sections; ‘parents’ expertise’, ‘negotiating and protecting the parental role’, ‘understanding new treatment technologies and treatment decision-making’, ‘recovery’ and ‘uncertainty.

#### 9.2.1 Parents’ Expertise

Chapter Seven explored the medical knowledge and work carried out by parents in the management of their child’s illness and treatment experience. Parents largely portrayed themselves as having extensive knowledge about their child’s tumour, its treatment options as well as the range of associated conditions and side effects, and how to manage these. Furthermore, parents were shown to have developed skills which enabled them take on tasks which would otherwise be carried out by a trained professional. Using Collin’s (2014) schema
for classifying expertise, this knowledge and practice was situated as expertise. Parents were found to be in possession of different types of specialist expertise; contributory, interactional and special interactional. These expertise were acquired and developed through their experience of managing their child’s illness, interacting with other parents, former patients as well as trained medical professionals such as specialist nurses, and merging this with their own unique knowledge of their child. Parents’ acquisition of expertise was also found to be facilitated by their occupational background and professional training, as well as their past experiences as a patient. It was demonstrated that parents utilised this knowledge and expertise in order to manage and navigate their child’s illness trajectory.

The notion of parents which emerged from the interviews was at odds with the redundant portrayal of them within the information leaflets. Within the documents, parents were largely portrayed as passive actors within the clinical encounter, and fitting within a traditional doctor-patient model, the onus of power and agency was placed on the medical professional. Nuances of an informed and empowered parent/patient emerged, however it appeared that information was imparted by and driven by the clinician. The knowledge and expertise which the parent(s) bring to the encounter and the complex knowledge and work that parents engage with during the course of their child’s illness was neglected.

The value and importance of parental expertise was demonstrated, where some parents spoke of their reliance on other parents’ niche areas of expertise, i.e. disease specific, or treatment specific. In some instances, parents relied on this expertise in order to supplement gaps in medical knowledge related to the effects of proton treatment, as well as the rare type of tumour their child had been diagnosed with. Proton therapy is a relatively new form of treatment, in comparison to X-ray radiation, and there are some areas of uncertainty and absent long-term
evidence; this is recognised and acknowledged by the NHS (Crellin 2018). In an effort to plug the gap involving some of the unknown entities of treatment, some parents rely on and seek information from fellow proton parents. Some parents drew from the expertise of fellow parents in order to form judgments about medical professionals’ practices.

Parents also distinguished the need for access to a specialised and unique type of knowledge, which the medical profession is unable to offer them. These parents spoke of having sought the ‘lived’ and ‘real experiences’ of their fellow oncology/proton families, in order to be able to respond to and manage their child’s experience of illness and treatment. This type of specialist knowledge is different to the expertise which the doctors and expert medical personnel can provide, for it is based on the lived and personal experiences of the illness and treatment. Analysis of information leaflets noted the absence of a patient and biographical account of illness and proton treatment. The content of the information leaflets was biased towards a biomedical model of the illness, where the capabilities of the technology were at the forefront of discussion. These parents’ accounts highlighted the importance of having access to the lived experiences of illness. This experiential knowledge was especially valued in the context of proton therapy, for reasons explained previously, and the requirement to travel; for example, parents were eager to learn from other families about how they managed their family during the period away from home.

Online support groups, largely the treatment specific group from which parents were recruited from as well as some disease specific groups, were found to play an important role in the acquisition and dissemination of parental expertise. The majority of parents spoke of having sought and accessed information related to their child’s illness and treatments via online groups. Furthermore, they also spoke of their contribution to these support groups and
mentioned their willingness to share and give back to these communities. It was noted however, that the numerous references to and the heavy reliance on online groups witnessed within these parents’ accounts may in fact be partly due to the fact that participants were recruited from an online group, and are therefore oriented towards participating and facilitating these support groups.

Analysis suggests that the attainment of expertise was partly driven by the impetus for control and to reclaim the loss of power experienced by parents during their child’s illness. Aware of the limits of their role, parents tasked themselves with learning as much as they could about their child’s condition and everything related to it in order to exert control over the situation, where possible. Attainment of expertise and the need to be knowledgeable about their child’s condition was also bound up with notions of ‘good parenting’. Emphasising their duty to take responsibility and be proactive in the care of their child was understood as a way for parents to protect the threat to their moral status and duty as parents. This is further summarised in the following sub-section.

9.2.2 Negotiating and Protecting the Parental Role

As described previously, the attainment of expertise was found to be partly driven by parents’ desire to protect their parental status and fulfil their responsibility towards their child. Failure to become expert, and maintain or achieve optimal health for their child, could otherwise be viewed as failure to fulfil one’s obligation and moral duty as a parent. Notions of good parenting also came to light in Chapter Six, which looked at parents’ practices and preferences towards decision-making involving their child’s medical treatment. Parents appear to negotiate their role in the context of the doctor-parent encounter, where ideals of good practice permeate talk about their role and responsibilities. Based on the view that doctors are the experts and
know best, some of these parents relinquish their responsibility and are content with the doctors leading decisions involving their child’s medical treatment. In parallel to this, parents also aim to fulfil their role and duty as parent, where they seek out agency and responsibility in the context of their child’s healthcare; this was especially apparent in the self-funded cases. Overall, there lies nuances of tension and contradiction in these accounts where parents describe themselves as conforming to social expectations of being a patient and a parent simultaneously.

Issues concerning the parental role and responsibility also emerged in parents’ post-treatment accounts, where they reflected on some of the difficulties and challenges parenting a child recipient of PBT has had on their other children, and their parental role towards them. The demands and disruptions brought about as a result of the child’s diagnosis and the need to travel abroad, and be absent from the family, hampered these parents’ relationship with their other children. Following the acute phase of illness and returning home from the proton centres abroad, parents worked on recovering and maintaining these relationships. This was especially apparent in cases where the one parent had travelled alone with the sick child, and left their other children behind; these parents spoke of the stress and worry involved in leaving their other children. This observation draws attention to the wider implications of a child’s illness on their family. The implications involved in the need to be away from home in order to access treatment, which will also apply to many patients when the two UK centres become fully operational, ought to be recognised at a service level.

In making these observations and drawing these conclusions, is important to recognise and be mindful of what Dixon-Woods and colleagues (2003) have previously stated about parents as research participants. Whilst parents will be motivated to provide insight into the private world
of childhood diseases, such as cancer, and present a ‘true account’ of the experience, in recounting the events and presenting their accounts they will also be aiming to protect their identities and those of their children in face of socially constructed notions.

9.2.3 Understanding Proton Beam Therapy and Treatment Decision-Making Practices

Chapter Six explored parents’ understanding of proton therapy and examined their practices towards decision-making involving medical treatments. Parents’ views and understandings of proton therapy was found to be partly facilitated by wider understandings and discourse surrounding radiation therapy and cancer treatments. It was found that widely held negative perceptions of radiation therapy prefigures some of these parents’ understanding of proton treatment, where they expressed concerns about the use of radiation treatment on their child. This finding is consistent with previous research which has found that misconceptions surrounding radiotherapy are thought to heighten patient anxieties and impact decision-making. Parents largely portrayed themselves as putting these negative associations aside however, after learning about PBT’s capabilities. Juxtaposing proton treatment with the conventional mode of therapy was a common model utilised by these parents in order to make sense of proton therapy. This comparison model highlights the features of PBT which distinguish it from X-ray therapy and adds to the allure of the technology. This leads to the view that PBT is superior to normal and conventional radiation therapy, albeit the lack of long-term evidence and research. Parents’ views of treatment are in line with the portrayal of proton therapy within the documents, especially the American produced items.

Various sources of information and factors had influenced and contributed towards parents’ views of proton therapy, and decision to opt for this treatment. Parents actively sought out information and were found to have relied on this in order to formulate a view of treatment and
decide whether they think it is suitable for their child. Some parents stressed the importance of making sure the information they accessed came from credible sources, where they made use of reliable websites as well as information relayed to them by healthcare professionals; these parents were wary of the sensationalised information out there about PBT. Parents also relied on information relayed to them by the doctors to help them understand the benefits of treatment and make a decision, where some parents made a distinction between the types of medical professional from whom they sought information and approval from; in these instances, the input of the experts from the proton centres were valued and sought. In formulating their views of treatment and making a decision, parents described seeking out information related to proton therapy, as well as tumour/disease specific experiences, from other parents and patients. The role and importance of fellow parents was acknowledged earlier; given than PBT is a new type of treatment, parents were keen to seek information from other users of the technology. A further consideration which was factored into these parents’ decision-making, was their unique knowledge and understanding of their child.

Despite the limited resources and available long-term evidence about the use and efficacy of PBT, most parents were satisfied with the decision made about their child receiving proton treatment; the side effects were largely at the forefront of the decision-making discussion and rarely any mention was made about the overall outcome of treatment on the child’s tumour. Within the non-NHS participants’ accounts, it appears that the conflict which arose between parents and doctors was due to their different preferences and views regarding the outcome of treatment. It was demonstrated that for one mother, the side effect profile of PBT preceded its efficacy to treat the tumour.
Parents’ preferences and practices involving treatment decision-making varied, with some describing taking on an active role and their desire to be more involved in decision-making, whilst others described being content with their passive role and allowing the clinicians to lead. In some instances, parents’ stance changed, and they alternated between passive and autonomous roles. Experience and the acquisition of knowledge throughout the child’s condition appeared to play a role, where some parents reflected on their initial lack of knowledge at the start of their child’s illness, and compared this to now and the knowledge they have acquired about treatment and disease. In line with other research in the field, these parents’ decision-making practices varied and evolved (Lipstein et al. 2012, Pyke-Grimm et al. 2006). With the view that doctors are the experts and therefore more adept to make treatment decisions, some parents were content with their passive role and others described wanting to relinquish the responsibility assigned to them and leave decision-making in the hands of the clinicians. This view shifted however, when parents gradually became familiar with matters related to their child’s illness.

9.2.4 Uncertainties

Three areas of uncertainty related to medical screening and surveillance, fear of relapse and proton treatment were observed in these parents’ accounts. Whilst the majority of parents spoke of clear scans and evidence of tumour disintegration, their accounts of their child post-PBT were embedded in the context of continued surveillance. The routine surveillance and long-term medical plans involved in monitoring their child were found to have facilitated the perception of the ongoing ‘presentness’ of disease. Similar to findings reported by Bell and Kazanjian (2011) the surveillance medicine seemed to blur the lines between risk and disease
state, heightening these parents’ uncertainty. The notion of ‘scanxiety’ emerged as parents’ response to and experiences involved in relation to the routine post-treatment scans and tests.

Uncertainty related to the fear of relapse emerged partly in relation to this surveillance. Despite their child being treated with a novel, and more advanced, form of treatment most parents could not be certain about the outcome of treatment. Parents were especially worried about the disease returning. Most of the children involved in this study had been diagnosed with a cancerous tumour. It was therefore noted that the wider discourse associated with cancer may have contributed to some of these parents’ experiences of uncertainty. The experiences of other parents and families were found to contribute towards some of these views. The rare nature of some of the cancers were also found to have contributed to some parents’ uncertainties, where they could not be certain of how their child’s tumour would behave. In some instances, the rare nature of the child’s tumour coupled with the novelty of PBT exacerbated some of these uncertainties.

Parents spoke of uncertainties related to proton therapy, where they explained that they cannot be certain about the outcome of treatment and the unfolding of side effects in the child’s future. The novelty of PBT and the limited long-term research heightened this uncertainty. In an effort to overcome some of these uncertainties parents relied on knowledge and expertise drawn from medical professionals, but most importantly sought the opinion and experiences of other parents and patients. Parents talked about relying on the subjective experiences of other families, parents and patients in order to manage some of the uncertainties they experience and to become better prepared about what to expect from treatment and how to manage these; parents’ attainment of expertise was also thought to be a response to some of these uncertainties.
9.2.5 Post-treatment Accounts of Recovery

Chapter Eight looked at how parents viewed their child’s recovery, following proton treatment. With a focus on the physical aspects of recovery, and the notion that recovery means a transitioning back to a healthy person (Parson et al. 2008, Radley and Taylor 2003), it was found that this aspect of recovery is unachievable for most children. Parents spoke of a range of short-term and long-term health complications, post-treatment, that their child suffers from. The accounts to emerge from these interviews were at odds with the depictions uncovered in the documents, and there are clearly gaps between the documents’ representation of PBT and users’ actual experiences involving treatment. Discourse analysis of the documents, in Chapter Five, revealed the focus to be primarily on what treatment is capable of doing at the site of disease, and the wider complexities of the proton experience and issues relating to post-treatment were largely overlooked. Proton treatment was widely depicted in the information leaflets as a highly effective mode of treatment and the overall side effect profile of treatment was downplayed. Where the subject of side effects was broached the discussion was primarily focused on the here and now of treatment and the post-treatment and long-term discussion took a backbench. However, as it emerged in the interviews, children treated with PBT suffer from a range of treatment related side effects; leading some parents to describe their child as being more ill post-treatment. Some of these issues were found to be an unexpected side effect of proton treatment, with parents explaining that no one had prepared or informed them about these.

In analysis of these post-treatment accounts, it was demonstrated that the child’s recovery is not only limited to physical recovery from illness. Echoing research in the field, which has primarily looked at adults’ experiences of recovery (Balmer et al. 2015, Foster and Fenlon 2011), parents spoke about the non-physical dimensions of their child’s recovery. Recovering
the ability to partake and carry out tasks, which were hindered by the acute phase of illness and treatment, were regarded as marked signs of improvement, which instilled a sense of normality for both parent and child. The child’s pre-cancer/treatment lives provided a yardstick against which these non-physical aspects of recovery were measured. For these parents, their child’s recovery was gauged by the ability to recover their past lives and identities. Some parents were found to frame perceptions of their child’s recovery, through the process of normalisation, whereby parents would juxtapose less able peers with the same condition against the abilities of their own child.

A core finding of this research is the assertion that aspects of recovery also related to parents’ experiences. Whilst parents talk about their child contending with the potential implications of the illness in the future, they also state that they themselves ‘learn to live with cancer’. In the context of normality and recovering this sense of normality, parents spoke of recovering their own identity and parental role, especially towards their partners and other children. Parents spoke of their other children and reflected on some of the difficulties and challenges parenting a sick child has had on their other children, and their parental role towards them. Parents were aware of the way siblings might feel because of changes to family practices and the focus being dedicated to their sick child. Parents were worried about their other children feeling left-out and explained that they made a conscious effort to recover and maintain the balance of parenting. These concerns were most acute in the families who had not managed to travel collectively to the States and who had been separated for a long duration of time. Parents explained that following the end of treatment and returning home from the States, they made effort to spend time with their other children and maintain their relationship with them.
9.3 Contributions to Wider Literature

This study has contributed to wider sociological literature in a number of areas; these are discussed briefly below.

9.3.1 Situating Expertise and Parental Expertise

This research situated parental knowledge and work, deployed in the management of their child’s illness, as expertise. Parents were found to have different types and levels of expertise. Collins’ (2014) framework of expertises was used to categorise this knowledge as expertise. An advantage of making use of this framework is that it is not addressing patient expertise, but rather the general question of expertise. Collins’ schema seeks to answer questions about how knowledge is acquired and how such knowledge can be classed as different forms of expertise. Underpinning Collins’ work is the view that lay people can acquire substantive levels of knowledge, despite not possessing forms of expertise and training necessitated to fit the popular notion of ‘expert’. Utilising this model enabled this study to address concerns and questions within sociological literature about how the nature of patient/lay expertise ought to be addressed (Prior 2003). Existing literature has either served to challenge the notion of patient expertise, or has offered a description of said expertise without any neat system of categorisation. When conducting the literature review for this research, I found engagement with literature which referenced parents’ expertise problematic, for it failed to explain why what they were describing actually constituted expertise. I also agree that the term ‘expert patient’ and ‘expert carer’ should not be used loosely (Fox et al. 2005, Prior 2003). Collins’ framework is therefore useful for it serves to define expertise.
This study has contributed towards to the body of literature within the sociology of health and illness, which aim to clarify the notion of expertise and patient expertise, by demonstrating the use and suitability of Collins’ framework (Green 2017, Collins 2014). This research has extended this literature by applying the framework of expertise to parents’ experiences, and situating their knowledge as expertise. This is different to the plethora of expert literature, for although not ill themselves, parents acquire and develop this expertise, by proxy, in the context of their child’s condition and its management.

9.3.2 Sociology of Recovery

A well-rounded conceptual framework for recovery from illness does not exist. One of the facets of recovery is concerned with physical aspects of recovery (Radley and Taylor 2003). Elsewhere, recovery is conceptualised as the ability to re-establish the continuity of selves and the maintenance and preservation of roles and relationships, in face of change (Foster and Fenlon 2011, Grant et al. 2009, Godfrey and Townsend 2008). Research examining experiences of recovery amongst cancer patients found that participants valued the ability to return to normal or at least maintain some level of normality (Balmer et al. 2015, Foster and Fenlon 2011); however, this literature is based on adult patient perspectives. Research examining recovery from the perspectives of young patients is scant; this research enhances this very limited research. This research did not have access to the voices of these young people, but is the first piece of research to examine notions of recovery, in the context of childhood illnesses, from the perspective of parents. Additionally, this research is one of the first to look at notions of recovery in the context of paediatric oncology patients; where the experiences involving children diagnosed with a CNS tumour are largely overlooked.
This research examined the way parents’ view and understand their child’s experience of recovery. Echoing similar findings to previous scholars (Balmer et al. 2015, Foster and Fenlon 2011), the child’s recovery was framed by these parents as a return to normality. The child’s pre-cancer/treatment lives provided a yardstick against which aspects of recovery were measured, and the child’s recovery was gauged by the ability to recover their past lives and identities.

This research has also drawn attention to parents’ own experiences involving recovery, following their child’s diagnosis and treatment. To this end, recovery from childhood illness is conceptualised as a joint venture, shared between parents and child. Parents spoke about accepting a new normal, whilst also talking about actively trying to repair the disruptions brought about to their roles and responsibilities, namely towards their other children. There is room to postulate recovery as the ability to achieve continuity of identity and relationships, which requires effort. Recovering their parental role and identity was described as an effortful, rather than a passive, process. This research extends sociological scholarship on recovery, by conceptualising recovery from childhood illnesses as non-linear and multi-dimensional experience, shared between parent and child.

### 9.3.3 Experiences Involving New Treatment Technologies

Given that PBT is a new type of treatment, this study set out to explore whether this factor bore influence on users’ experiences. Based on the fact that proton treatment is largely pitched based on its abilities to reduce side effects and improve patient’s quality-of-life, as compared to other treatments, this study was interested in exploring whether experiences of recovery attached to this treatment are any different to other cancer patients. Decision-making was also an area of interest; taking into account the novelty of the treatment technology, in comparison to well-
known and conventional modes of cancer therapies, it was not known what sources of information, experience and discourses parents may draw from in order to model their views of treatment and base their decision-making on.

This study has established that despite the innovative nature of proton treatment, users of the technology share similar experiences to other patients and users of conventional cancer therapies, as described in the wider literature. Previous studies have demonstrated that uncertainty is a common feature of cancer patients’ experiences (Williams et al. 2017, Halkett et al. 2012 and Roberts and Clarke’s 2009). The role of novel treatment technologies as a source of uncertainty has also been identified (Parry 2003, Stewart and Mishel 2000, Cohen 1995). Collectively, these uncertainties can distort notions of recovery and efforts on the sufferer’s behalf to instil normality (Radley and Taylor 2003). In chapter eight it was demonstrated that similar expressions of uncertainty were recounted by parents of children who had been treated with PBT. Despite the promise of reduced side-effects and a better quality-of-life, the novelty of this technology and the consequent lack of evidence created room for post-treatment uncertainties and impeded any sense of recovery.

9.4 Strengths, Limitations and Reflections

In evaluating the limitations of this study, the primary method of recruitment, i.e. online support groups, could be considered as a potential limitation based on the sample of participants it has yielded. The sample is limited in a number of respects. Having primarily recruited via the support group means that the sample is more indicative of families who are members and users of the online group, and therefore the broader population of proton families is overlooked. Recruitment from the online communities may have also created bias in the
findings which have emerged; users of support groups may be more inclined to seek and share knowledge, and their group membership may be as a result of their proactive stance. Recruiting from other support groups and employing other means of access to participants may have served to diversify the sample. Despite efforts however, the online support group acted as the primary gate to participants. A further limitation of this study is the small sample size; however, as highlighted and discussed in Chapter Four, whilst the number of interviews fell short, the number of interviewees recruited represent a reasonable proportion of the overall target population. Additionally, theoretical saturation was reached and therefore findings can be theoretically generalised.

Despite the limitations discussed above, the recruitment method indeed strengthened the design of this study since it enabled me to target a small group of patients and users of proton treatment, and yield a decent number of participants. The fact that there are no other Proton Beam Therapy specific support groups, online or offline, available for UK based patients may have benefited my research in this way. And whilst the argument holds true in terms of the bias which recruiting from support groups may yield, the counter argument to make use of support groups is that these groups are venues where people are more willing to talk about and discuss emotive issues. Recruiting participants from these venues can therefore be a strength, which is reflected in the depth and richness of the data produced by these parents. Online support groups are also, generally, geographically independent (Stommel and Koole 2010), and this is reflected in the geographical spread evident in my sample.

In the initial design of this study I was aiming for a multi-perspective view of the issue under investigation and proposed a study which included the recruitment of NHS based clinicians, parents and their children, who had been treated with PBT. Constraints imposed by the ethics
committees meant that I was only able to recruit parents. The time constraints which frame a PhD study resulted in my decision to eliminate children from the study, since I could not afford the time lost if the ethics panel were to reject my application again. This was a difficult decision for me to make, since as a researcher I value the inclusion of children and young people’s input into research concerning them. Whilst the NHS ethics committee issued an unfavourable opinion in light of the distress it could cause for parents and children, my research experience suggests that some parents were in fact eager for their child to contribute to the interviews. Children, too, were also eager to talk about their experiences, although I did not interview them. Whilst I do recognise the sensitivity of the issues highlighted by the ethics committee, I would argue that the parents and children (depending on their age and circumstances) should be given autonomy to consider this decision about participation, based on the information provided to them. It is plausible to suggest that such limitations and constrained imposed by ethics committees, designed to protect the vulnerable, in fact exclude certain populations of people from research. Notwithstanding the range of difficulties and health complications of the population of paediatric oncology and CNS patients which prevents them from participating in research studies, excluding them due to said constraints may also be reason for the gap in literature concerning their experience. Setting out to incorporate the views of young paediatric patients who travel for PBT treatment can be an avenue for further research. Additionally, there is also scope to explore and contribute to methodological debate concerning young research participants and sensitive topics.

It is also worthy of mention that recruitment for this study commenced shortly after the high-profile case of Ashya King, and my initial round of recruitment was therefore met with a level of skepticism. Following my initial post to the online support group I immediately received a number of emails from clinicians, who had been contacted by members of the group who had
seen my post and considered it to be a possible journalistic ruse to gather information in relation to the King case. I was asked for proof of my academic credentials by these clinicians and parents. Whilst I aimed to clarify my position in the group and assure members of my intentions, there is no knowing whether this initial skepticism and response to my recruitment drive prevented others from coming forward to take part in the study. Whilst the topic of cancer is no doubt an emotive topic, in the case of this study it also proved to be extra emotive due to the political sensitivity of the topic, which appeared to act as a challenge and threat to the medical cohort. This sensitive climate was one of the contributory factors which deterred me from recruiting clinicians and limited my research in this respect.

9.5 Future Research Avenues

Despite efforts to recruit fathers to this study, only a limited number of fathers participated. The majority of findings related to parental role, recovery and expertise are largely based on mothers’ accounts. Further research could look at fathers’ experiences specifically and to see whether similar findings emerge. However, recruiting fathers is known to be a difficult challenge within the realm of sociology of health and illness enquiries; this is partly due to the fact that mothers take on more caring roles in their parenting practices and are more accessible as research participants. A future study needs to be mindful of this and aim to make use of recruitment initiatives which encourage fathers’ participation. A further research study would also set out to recruit from other channels, in order to eliminate the bias limitations mentioned earlier, especially in relation to parental expertise.

Children, especially paediatric oncology patients, are largely neglected within research. There is very limited research looking at how children view and experience recovery. Examining
children’s experiences of recovery is a possible area of future inquiry. Whilst exploring their understandings and views of recovery, it would be interesting to see whether they conceptualise recovery similarly to adult patients and parents. Additionally, a joint study involving children and their parents could examine whether parent(s) and child share similar views and goals about the child’s recovery. Additionally, I would be eager to incorporate the views and experiences of siblings.

The travel element is an important part of the proton experience, but was not explored extensively in this research. With the introduction of the proton centres in the UK, the travel element will still persist. Further research could look at experiences of displacement from home, involved in accessing treatment.

**9.6 Conclusion**

This research has examined the experiences of parents of paediatric patients, treated with proton therapy. This is the first piece of sociological research to have examined users’ experiences involving proton therapy. Similar to practices reported in the literature concerning treatment decision-making, parents were shown to draw from various sources of information and wider discourse, in order to formulate their views of treatment and manage decision-making. Given that PBT is a new form of treatment and long-term evidence pertaining to the effects of treatment is absent, the ‘lived experiences’ and knowledge of fellow parents and families were especially valued and sought, in order to plug the gap in some areas of medical knowledge. It was demonstrated that through their experiences of caring for and managing their child’s illness, parents develop niche pockets of expertise. These findings have contributed to the sociology of health and illness by conceptualising parents’ knowledge and experience as expertise. Additionally, this
research also looked at what a child’s recovery, following PBT, means from the perspective of their parents. Findings to have emerged from this study enhanced the very limited research available on the experiences of paediatric oncology patients, and their experiences of recovery. This study has also revealed that in the context of childhood illnesses, parents undergo a process of recovery. To this end, recovery from childhood illnesses was conceptualised as a joint effort shared between parents and child. Parents make a conscious effort to recover their role and identity, which had been compromised as a result of their child’s illness. Overall, this research has demonstrated the value and importance of parental knowledge and experience, and has drawn attention to impact of a child’s illness on their parents. Additionally, it has shed insight into practices and preferences involving a new medical treatment.
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Appendices:

Appendix (I) – Who can be Referred and Funded for Treatment Abroad?

Who can be referred and funded for treatment abroad?

It is important to recognise that funding will not be approved outside the strict criteria of the approved diagnostic list and with reference to the accompanying notes. The fact that a patient has a diagnosis on the approved list does not imply that protons will necessarily or always be the preferred radiotherapy option. It should be noted that final decision to accept cases for treatment after approval from the PCRP is made by the treating centre.

Some additional and over-riding principles for approval and funding are important. These are:

- Treatment should be given with curative intent
- Patients will have good performance status
- No other coincident diagnosis that are likely to either limit 5 year survival or make a prolonged period abroad difficult to manage from a practical point of view
- There should be no metastatic disease
- Re-treatment cases will not be accepted
- There are weight limits on the treatment couches in treatment centres. The weight of adult patients at the time of referral should be given and should not exceed 150kg.

Cases with the clearest indication are adult and paediatric patients with base of skull chordoma and chondrosarcoma or primary paraspinal tumours. Many of these tumours will have had some degree of surgical resection or debulking. It is clear that any advantage of proton treatment over optimal photon treatment may be dependent on the size and position of the tumour and target volume in relation to critical normal tissues and tolerance doses. In some cases the treatment centre may require further debulking surgery before they are accepted for treatment. Cases may be turned down when, in the panel’s view, proton therapy would not confer any advantage. The definition of ‘paediatric’ is taken as up to but not including the 16th birthday at the date of receipt of a complete referral to the panel. Equivalent diagnoses/tumours will not normally be approved in the adult age group.
A wide range of factors need to be taken into account in assessing if Proton Therapy confers any significant advantage over conventional radiotherapy or IMRT. The diagnosis alone is often not sufficient. These factors include the:

- timing of radiotherapy in relation of other treatments
- site of tumour
- radiotherapy target volume
- target volume dose and dose gradient required
- tumour and target volume proximity to critical dose limiting structures
- patient age and performance status
- stage and pathology
- presence, size and position of metallic implants
- views of patients/parents
- patients ability to travel

Source: NHS 2011
Appendix (II) – Consent Form (Single Interview)

Consent Form (Single Interview)

Please complete (initial your name) this form after you have read and understood the Information Sheet. If you have any questions or concerns arising in relation to this research, please ask and consult the researcher before you decide whether to take part. This study has been reviewed and received a favorable ethical opinion by the University of Surrey Ethics’ committee.

I the undersigned voluntarily agree to take part in the study entitled: ‘Childhood cancer and Proton Beam Therapy: an investigation into clinician and parent(s)/carer(s) perceptions and experiences’.

I confirm that I have read and understood the Information Sheet (Version 1, 16/9/15) provided. I have been given a full explanation by the investigator of the nature, purpose, location and likely duration of the study, and of what I will be expected to do.

I agree and understand that I will be interviewed by the researcher.

I understand that participation is voluntary and I am free to withdraw from the study at any time without needing to justify this decision and without prejudice. At any point that I wish to withdraw my participation, all personal data and identifiable participatory data contributed by me to the research will be withdrawn and destroyed.

I understand that the interview will be digitally recorded for the purpose of analysis and that all information retrieved will be held and processed as strictly confidential and in accordance with the Data Protection Act (1998).

I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions of the study.

I understand and agree that data collected about me will be used and published for this study, without me being identifiable.

I agree to the use of anonymised quotes in reports and publications.

I agree and understand that my anonymised data may be archived and subsequently used by other researchers. I understand that my personal data will not be shared.

I confirm that I would like to be contacted by the researcher regarding findings from this research.

Name of research participant (BLOCK CAPITALS):

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Signature:

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NB: please note this consent form will be stored safely and separate to the collated data

Version 2, 18/07/15
Appendices

Consent Form (Single Interview)

Date: ..............................................................................................................................................

Name of principle researcher (BLOCK CAPITALS):
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Signature:
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Date:
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NB: please note this consent form will be stored safely and separate to the collated data

Version 2, 18/07/15
Appendix (III) – Consent Form (Joint Interview)

Consent Form (Joint Interview)

Please complete (initial your name) this form after you have read and understood the Information Sheet. If you have any questions or concerns arising in relation to this research, please ask and consult the researcher before you decide whether to take part. This study has been reviewed and received a favorable ethical opinion by the University of Surrey Ethics’ committee.

I the undersigned voluntarily agree to take part in the study entitled: ‘Childhood cancer and Proton Beam Therapy: an investigation into clinician and parent(s)/carer(s) perceptions and experiences’.

I confirm that I have read and understood the Information Sheet (Version 1, 16/9/15) provided. I have been given a full explanation by the investigator of the nature, purpose, location and likely duration of the study, and of what I will be expected to do.

I agree and understand that I will be interviewed by the researcher.

I understand that participation is voluntary and I am free to withdraw from the study at any time without needing to justify this decision and without prejudice. At any point that I wish to withdraw my participation, all personal data and identifiable participatory data contributed by me to the research will be withdrawn and destroyed.

I understand that the interview will be digitally recorded for the purpose of analysis and that all information retrieved will be held and processed as strictly confidential and in accordance with the Data Protection Act (1998).

I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions of the study.

I understand and agree that data collected about me will be used and published for this study, without me being identifiable.

I agree to the use of anonymised quotes in reports and publications.

I agree and understand that my anonymised data may be archived and subsequently used by other researchers. I understand that my personal data will not be shared.

I confirm that I would like to be contacted by the researcher regarding findings from this research.

Name of research participant (BLOCK CAPITALS):

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Signature:

NB: please note this consent form will be stored safely and separate to the collated data

Version 1, 18/07/15 (Consent form for joint interviews)
Appendices

Consent Form (Joint Interview)

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Date: ...........................................................................................................................................

Name of research participant (BLOCK CAPITALS):
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Name of principle researcher (BLOCK CAPITALS):
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Date: ...............................................................................................................................................
Appendix (IV) – Interview Topic Guide

Discussion Guide

Discussion Guide

To be used in both single and joint interviews with parents/carers

The researcher will agree with interviewees how much time they have available prior to the start of the interview.

The questions below indicate the areas to be covered in the interview.

[Introductions]
[Process to check and record consent]

1. Background

- To begin with, can you tell me a bit about yourself and your child?
- What terms do you use to talk about the illness within the family? Are there any words you avoid using? [If applicable, the substitute terminology will be used throughout the interview in order to avoid use of the word cancer]
- Prompt for:
  - Single parent or living as a couple
  - Occupation/unemployed? Whether employed prior to their child’s illness.
  - Number and ages of children living in same house and elsewhere
  - Age of child undergoing Proton Beam Therapy
  - Type of cancer
  - Approximate diagnoses date

2. Diagnosis and decisions regarding initial treatment

Initial open-ended question to elicit narrative:

- Starting from the beginning, can you please tell me when you first suspected a problem with your child’s health and what happened from there?

Follow up/ prompt questions:

- What were the symptoms/concerns that led you to believe your child was unwell?
- Did your child complain about feeling unwell? Did you notice something which caused you concern?
- Did you go to your GP or visit A&E?
- What tests did your child undergo?
- How was the diagnosis made? Who told you? How did they explain this to you?

Version 1, 16/9/15
Discussion Guide

- What information were you given? Were there other things you wanted to know at that stage? Did you look for information from other sources?
- At what point did you become aware of the seriousness of your child’s condition? Did you suspect it prior to the doctor’s official diagnosis?
- What did you know about your child’s condition/what did the doctors tell you?
- Did you seek information from other sources? (probe use of internet, social media, other parents, mumnet, newspaper, magazines, helplines, acquaintances etc)
- What treatments has your child had so far? What further treatment is planned?
- How did the doctor explain the treatment plan for you? Was there a discussion about different options? How was information presented to you? - - Have you sought information in other ways (e.g. internet, Facebook group, helplines, acquaintances etc)
- Have you talked to your child about their illness? (If they have siblings, did you talk to your other children about their brother/sister’s illness/diagnosis?)
- How do you talk to your child about what is happening with their treatment and medical procedures? Has a health professional talked to them directly about their illness or their treatment?

3. Proton Beam Therapy

- Check details of Proton Beam Therapy – when and where the child received treatment, for how long and how funded?
- What you understand by Proton Beam Therapy? Can you explain it to me?
- Can you remember when you heard about PBT? Where did that information come from? How was PBT described?
- Who first raised the possibility of PBT as a treatment for your child?
- **(If doctor introduced possibility of PBT)** Were you told of the possibility from the moment you child was diagnosed? Or did they reach a certain point in their treatment when the doctor decided that PBT would be appropriate? What do you remember being told about the reasons for choosing this mode of treatment for your child’s illness? What were you told about the process for seeking approval for funding?
- **(If parents asked the clinical team about PBT)** When did you raise the possibility of PBT with the medical team treating your child? How did they respond? What then happened?

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- What was the state of your child’s health at the time PBT was first discussed?
- Do you think you were given enough information about PBT? Were there other things you wanted to know at the time or have wanted to know since?
- How do you view PBT as part of the range of treatments your child has received for their illness?

4. Referral process for PBT
- Can you tell me about the decision making/referral procedure involved for PBT?
- Were you asked your opinion about PBT before an application was made for your child to have this treatment? Did you formally agree to this treatment or was it more that this was the best treatment for your child?
- Were you given time to think about PBT before your child was referred? (If given time) How long? Did you involve or consult anyone else about the decision (family member, other health care professional, other source of information)?
- Was the fact that you would have to go abroad for this treatment something you thought about? (If yes) what did you think about going abroad for treatment?
- Did you talk to your child about this treatment?
- Did a health professional talk to your child about this treatment?
- How were you prepared for the panel’s decision?
- Were you aware of the eligibility criteria/factors that would be taken into account in deciding whether to fund your child’s treatment?
- Were you aware of the possibility of your child’s case not being approved by the panel? How had you prepared for this?
- How long did you have to wait before hearing the panel’s decision? What happened during the time you were waiting for the decision? (other treatment, child’s health, other events)

- **NHS pathway/approved…. what happened next?**
  - How were you made aware of the panel’s decision? Who told you? What did they say?

- **NHS funding not approved / appeal / found alternative funding…. What happened next?**

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- How were you made aware of the panel’s decision? Who told you? What did they say?
- Did you appeal? What happened?
- Why was it so important to you for your child to be given PBT?
- How/where did you source alternative funding?
- What happened in terms of your child’s health/medical treatment during this time?

5. Travelling abroad for treatment

- How long did you have to prepare for going away between referral and actually travelling to [PBT centre]?
- What were the practical things you had to do? Arrangements for accommodation? Tickets? Travel insurance? Work? Care of other family members?
- What information were you given by your child’s clinical team in the US? Did you look for other information? (What? How?)
- Did you have concerns about your child’s health whilst travelling?
- How was the journey? Did you have to learn any skills/prepare for any possible medical complications?
- Who travelled with you?
- How did the need to be away from home affect your job / family / responsibilities at home / financially / other?
- Do you know how your child felt about travelling away from home?

6. Proton Beam Therapy Treatment Centre

- What was the PBT treatment centre like? Was it as you expected? Was (how was) the PBT centre different to your child’s treatment centre in the UK?
- How long was the course of treatment?
- Did your child undergo treatment every day?
- What did treatment involve?
- How was this different to other treatment they had had previously? Side-effects?
- Did your child have to go under general anaesthetic for treatment?
- Were you present during treatment? Were you able to observe from nearby? What did you do whilst your child underwent treatment?
- Did your child undergo other treatments as well as PBT?

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- What do you think of the health care professionals in the PBT centre? Nurses? Specialists? Others?
- Were you in contact with your child’s clinical team in the UK during the time you were abroad?
- Did you have any concerns about going to this new treatment centre and leaving behind your child’s previous healthcare team?
- How long were you away for? Was that the amount of time you had expected to be away? (Probe for reasons why longer/shorter than planned.)

7. Returning home following Proton Beam Therapy
- Can you tell me about settling back into life at home after your child’s treatment...
- How has your child’s health been since returning home?
- What, if any, treatment has he/she received since coming home?
- Who is managing your child’s care now?
- Do you know anything about the handover arrangements from the PBT centre back to your local clinician?
- Have you had any concerns about not being within close range of the clinicians and nurses from the PBT centre?
- Do you know whether a follow-up visit to the centre is planned?
- Is other treatment planned?

8. Reflections
- How are things looking now in terms of your child’s health?
- Is there anything you wish you had known prior to it all?
- What advice would you give to another family who is about to embark on the same journey as yourself and your family/child?
- Looking back, do you feel you were listened to by health professionals?
- Do you have any advice for health care professionals who deal with young patients diagnosed with [name of cancer] and their families?
- Do you have any advice for health professionals concerning PBT and the referral process?
- Could you summarise/reflect on the whole experience and the impact of the illness on: Your child? Yourself? Your family?

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- Is there anything you would like to add?

[Draw interview to a close]
* Due to the narrative nature of the interview, it is anticipated that all questions detailed above will not be covered. This is merely a discussion and prompt guide.
Appendix (V) – Recruitment Poster

An investigation into parent(s)/carer(s) and clinician, experiences of Proton Beam Therapy

Has your child recently received Proton Beam Therapy as part of their treatment?

Did you accompany them to the treatment centre?

If you have answered YES to these questions, then you and your partner are invited to take part in a research study which seeks to investigate parent(s)/carer(s) experience of their child’s Proton Beam Therapy and of travelling a long distance from home for treatment. What are your thoughts on the access route in place for this technology? What factors strengthened and weakened your experience?

To take part in this study:
- You must be based in England, UK.
- Your child must have been treated with Proton Beam Therapy.
- You are welcome to take part in this study individually, or with your partner,
- If you take part as a couple, at least one of you should have travelled to the treating centre with your child.

To find out more about this study or if you are interested in taking part, please contact me on n.haertkadeh-yazdi@surrey.ac.uk, or send me a Facebook private message.

Recruitment will end on the 31st July 2016.

This study has been reviewed and received a favourable ethical opinion from the University of Surrey Ethics Committee.

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Appendices

Appendix (VI) – Participant Information Sheet

Participant Information Sheet

An investigation into parent(s)/carer(s) and clinician experiences of Proton Beam Therapy

I am a PhD student based in the Department of Sociology at the University of Surrey and would like to invite you to take part in a research project about you and your child’s experience of Proton Beam Therapy so that the perspectives of young patients and their families are reflected in research. Before you decide to participate, it is important that you understand why the research is being undertaken and what your participation will involve. Please take time to read the following information carefully. If you require any clarification or would like further information, please contact me using the contact information listed at the end of this sheet. You can talk to others about the study if you wish.

You are welcome to take part in this study individually, or with your partner. If you take part as a couple, at least one of you should have travelled to the proton treating centre with your child.

What is the purpose of the study?

I am interested in learning about young patients and their families experience of Proton Beam Therapy. I would like to explore your experience as a parent/carer and what has happened to you when accessing this treatment outside of the UK. I am also interested in the referral process for Proton Beam Therapy and your experience of travelling a long distance from home in order for your child to receive treatment. Comparatively little is known about the illness experiences of families, children and young people who receive treatment with Proton Beam Therapy outside of the UK.

Why are you being asked to take part in this research?

You are invited to take part in this research based on either your individual experience as a father/mother/carer, or joint experience as parents. You are welcome to take part in this research as a couple or individually. This means that you will be invited to take part in a single interview or a joint interview, whichever you prefer. The interview would last about 1-1 ½ hours and would take place in a setting of your choice.

You are being invited to take part in this study since you are the parent/carer of a child who has recently received Proton Beam Therapy. Access to this treatment may have been granted via the NHS or a non-NHS funding pathway e.g. charity or self-funded.

Do you have to take part?

No you do not need to take part in the study as participation is voluntary. You can request for your personal information to be withdrawn at any time and without giving
Participant Information Sheet

reason. If you wish to withdraw from the study, please let the researcher know. Following your request, all personal data will be destroyed.

Your identifiable participatory data will also be retracted and destroyed. However, some data which is not identifiable may be retained since it cannot be traced back to you. You can request for your participatory data to be withdraw until the end of September 2016.

Your decision about whether to take part or withdraw from the the study will not affect you or your child’s treatment.

What will happen if you agree to take part?

If you are interested in taking part in this study, please contact me using the contact information listed at the end of this sheet. You can contact me via email or mobile phone, in order to discuss any details, questions or concerns you may have about the research.

You will be invited to take part in an informal interview at a convenient time and location. The duration of the interview will depend on the joint or single nature of the interview, but is expected to last between 1-1 ½ hours. The interview will involve a series of open-ended questions in relation to your experience. However I am interested in examining your unique experience and therefore invite you to reflect on and discuss any aspect of the experience which is important to you.

What happens if you initially decide to take part as a couple, but then one of you has to drop out?

There is no problem if either you or partner chooses to withdraw from the study. You can continue participation in the study and take part in a single interview.

However, if you have both taken part in a joint interview, but either one of you decides to opt out of the study, the entire interview an any information collected will be withdrawn from the research.

Will taking part in the study be confidential?

Yes. All personal information collected during the course of the research will handled in accordance with the Data Protection Act (1998). Information will be kept strictly confidential and anonymised so that readers of the published research are not able to identify or know who has contributed towards it.

With your consent the interview will be audio recorded, transcribed and processed for the purpose of analysis. During the course of the interview, the researcher may take additional notes for the purpose of analysis. Please note that you will not be named in any of the transcripts and that the researcher will protect the anonymity of all participants. Direct quotes used within any publication will be strictly anonymised.

What are the possible disadvantages or risks of taking part?

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Participation in this study involves a moderate time to take part in the interviews. Every effort is made to ensure the meeting is scheduled at a convenient time for you and you are welcome to take breaks where necessary. The duration of the interview depends on you and how much you wish to share with the researcher.

In order to avoid undue distress and discomfort, it is asked that your child is not present during your interview. However, based on the topic of discussion you may become emotionally distressed; if this is to occur you can ask to pause the conversation or end the interview.

What are the possible benefits of taking part?

There are no direct benefits to you or to your child in terms of their medical treatment. However, you may find the experience interesting. You will be contributing towards the current knowledge and literature on the experiences of childhood cancer, whilst also taking part in one of the earliest research projects related to PBT.

What will happen to the results of the research study?

In accordance with the University of Surrey’s policies, research data will be stored securely at the university for at least 10 years.

Data gathered and analysed for the purpose of this research will be written up as part of my PhD thesis. Additionally, findings of the study will be published in academic journals and presented at conferences, without you being identifiable. Please indicate on the consent form, whether you will like to be contacted by the researcher about the outcome and findings of the study.

The research findings will be of interest to clinical staff, policy makers and cancer charities.

What happens if there is a problem?

If there are any concerns or complaints about any aspect of the research, please let me know. Alternatively you can contact my supervisors Dr Rob Meadows or Dr Christine Hine or the head of my department, Professor Rachel Brooks. Their relevant contact information is provided at the end of this sheet.

This research has been funded by the Economic and Social Research Council.

Ethical approval

This study has been reviewed and received a favorable ethical opinion by the University of Surrey Ethics’ committee.

Thank you for spending time to read this information

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### Participant Information Sheet

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**Head of School:**
Professor Rachel Brooks  
School of Sociology, Faculty of Arts and Human Sciences,  
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**List of useful links to relevant helplines and support groups:**

- The Children’s Cancer and Leukemia Group (CCLG) offer a list of helplines, support groups, links to relevant charities and information websites. You can find out about your local support group by visiting their webpage at:  
  [http://www.cclg.org.uk/family-focus/useful-links](http://www.cclg.org.uk/family-focus/useful-links)

- CLIC Sargent provides information and support for parents who have a child recently diagnosed, or living with cancer. Please visit their webpage for further information:  
  [http://www.clicsargent.org.uk/content/parents](http://www.clicsargent.org.uk/content/parents)

- Macmillan support line: If you have any worries, questions or you just want some to listen, you can call the Macmillan support line on 0808 808 0000 (Mon-Fri, 9am – 9pm), or join their Online Community and talk online

For children and young people:

- CLIC Sargent has produced a number of publications to help children understand cancer and their treatment. Please visit the following link:
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http://www.clicsargent.org.uk/content/publications-children

- CLIC Sargent offers information and support for young people (aged 16-24) who have recently been diagnosed, or are living with cancer. Please visit the following link: http://www.clicsargent.org.uk/content/young-people

- The Children’s Cancer and Leukemia Group (CCLG) offer a list of various organisations, support groups and information links for children and teenagers diagnosed with cancer. Please visit the following link: http://www.cclg.org.uk/family-focus/useful-links/kids-and-teens

- Childline provides a confidential counselling service for any child with any problem. There is a helpline and a live chat service on their website. Please visit the following link: www.childline.org.uk
  Phone: 0800 1111 (24 hour freephone)
  Weston House, 42 Curtain Road, London EC2A 3NH

*Please note that recruitment to this research will end 31st July 2016*